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TITLE: Primary Care and Regular Breast Cancer Screening Among
Under-Served Minority Women

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13. ABSTRACT (Maximum 200 words) Purpose: To examine features of the primary care structure and process that promote regular breast cancer screening for under-served minority women. Scope: An existing data-base of 2600 multi-ethnic persons and their cancer screening behaviors from New York City was analyzed (year 1). Building on these analyses, additional features of primary care delivery systems which promote regular screening for women were examined via focus groups (Year 1); and, will be further assessed with a population-based telephone survey of minority women living in medically under-served areas of Washington, D.C. (Years 2-3). Finally, a primary care intervention will be developed (Year 4) to increase regular screening by clinical breast exam and mammography which will be implemented in the future under separate funding. Major Findings: Further secondary analyses of the NYC multi-ethnic data were pursued (in addition to those completed during year 1) resulting in a publication in the <i>American Journal of Preventive Medicine</i> entitled, "Are We Getting the Message Out to All? Health Information Sources and Ethnicity." This analysis focused on the health and cancer information sources used by the largest black and Hispanic ethnic groups living in New York City. The P.I. presented findings from these analyses at the American College of Preventive Medicine's national meeting, PREVENTION99, receiving the award for best faculty poster. A second manuscript resulting from the findings of the four focus groups (conducted during year 1) was submitted for publication and is under the final stage of review at the <i>Journal of Family Practice</i> . During year 2, the survey was developed. Funding was successfully obtained in the form of a small grant (RO3) from NCI to expand the survey proposed in the original Dept of Army application from a clinic-based convenience sample of lower income minority women, to a population-based telephone survey of lower income, minority women living throughout the medically under-served areas of Washington, D.C. This survey was successfully piloted (year 2); and, will be conducted during the first half of year 3, with resulting data analyzed by the P.I. during year 3.					
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FOREWORD

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Chris McCall 8/2/99
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1.0 Introduction

The overall goal of this study is to describe the components of primary care associated with adherence to regular breast cancer screening among low-income minority women. The proposed study pursues this goal by investigating features of the structure and process of primary care structure which are associated with breast cancer screening for minority women via: 1) analysis of an existing data-set of 2,600 multi-ethnic minority persons in New York City (NYC). Building on this, 2.) additional features of primary care delivery systems which promote regular breast cancer screening for under-served minority women were examined in four Washington D.C. primary care clinics. This Washington D.C. based phase includes a.) a qualitative component (focus groups) and b.) a quantitative component (survey). Finally, in conjunction with patient and provider representatives from local primary care clinics, an intervention will be developed to increase regular screening by CBE and mammography that will be implemented in the future under separate funding.

2.0 Body:

The following is an account of the progress made in the second year toward meeting the objectives specified for the study "Primary Care and Regular Breast Cancer Screening for Under-Served Minority Women," funded by the Department of the Army as a Career Development Award.

The Specific Aims of the study are as follows:

1. To investigate features of the primary care system which are associated with higher rates of breast cancer screening for minority women, using an existing data-set of 2,600 Caribbean-, Haitian- and U.S.-born blacks, and Puerto Rican, Dominican, Colombian, and Ecuadorian Hispanics living in NYC. (Year one-completed)

2. To conduct additional examinations of the features of primary care delivery systems which promote regular breast cancer screening for under-served minority women in four Washington D.C. primary care clinics. (In progress)

a. To conduct a focus group of the D.C. clinic patients and providers about perceived barriers to getting regular screening within their primary care systems. (These focus groups will include members of the advisory boards from the primary care clinics). (Year 1 – focus groups completed)

b. Using focus group input and preliminary analyses from Aim 1, we will develop a survey focused on features of primary care systems and regular screening. (Year 2-survey developed)

c. To administer the survey to 516 women in four primary care clinics to probe their perceived barriers to regular screening and their breast cancer screening practices. (Survey will be administered in first half of year 3)

d. To provide feedback on the survey results to the primary care clinic advisory board representatives. (Year 4)

3. To develop, in conjunction with the patient and provider representatives from the four primary care clinics, a primary care intervention to increase regular screening by CBE and mammography which could be implemented in the future under separate funding. (Year 4)

2.0 Progress Report August 1, 1998-August 1, 1999**2.1 Revision of protocol since original application:****2.1.1 Change from a clinic-based survey to a population-based telephone survey:**

For several reasons related to the quality of data and research questions, the P.I. and her mentors felt that a population-based telephone survey of women aged over 40 in the District of Columbia's lower income areas would be a preferred approach to the use of in-clinic interviews at just four clinic sites. The reasons and limitations of the new approach have been outlined in the table below:

<u>Original Proposal to Dept. of Army</u>	<u>Enhanced Proposal</u>
(In-person interviews at four primary care clinics)	(Population-based telephone survey of lower-income women from throughout Washington, D.C.)
<p>Strengths:</p> <p>May be less threatening to respondent than a phone call</p> <p>Could more easily include a validation of self-report of screening (Though this was not budgeted for under proposal)</p>	<p>Strengths:</p> <p>Random sample</p> <p>More representative of all low-income women throughout D.C., not just a convenience sample of users from a few community clinics</p> <p>Includes non-users and low-users</p> <p>More efficient sampling strategy</p> <p>Primary care sites analyzed would not be limited to just four sites</p>
<p>Limitations:</p> <p>On-site clinic interviews may lead to response bias, i.e. women reluctant to say negative things about their care when in the clinic</p> <p>Results would be less valid, i.e. not as generalizable to low-income women from other sites, or who are low or non-users of clinic services</p> <p>On-site bilingual interviewers is very resource intensive</p> <p>On-site interviewing was felt to be a burden for the clinic's and their available space</p> <p>On-site interviewing is less confidential for the respondent than a phone interview in the privacy of their own homes</p> <p>Much longer time is required to recruit women meeting inclusion criteria for study than in a population-based phone interview</p>	<p>Limitations:</p> <p>Does not capture persons without phones</p> <p>Validation of self-report of breast cancer screening, should we decide to do it later on, is more difficult since people are from many different primary care sites</p>

2.2 How the revised protocol will be funded:

In December of 1998, the P.I. submitted an RO3 application to NCI for research costs of the telephone administration phase. This application budgeted for money for contract out just the phone phase of the survey's administration. The budget did not include any request for the P.I.'s salary. There was no budgetary overlap with the Dept. of Army Career Development Award proposal.

The P.I. was notified of her priority score (121) and the high likelihood that this RO3 application would be funded by NCI in August, 1999. While she has still not received the funding from NCI, negotiations between Georgetown University and NCI are underway.

The P.I. notified her project officer from the Dept. of Army at the time that she applied for the RO3 to be sure that there were no conflicts from the Dept. of Army's perspective. The P.I. was assured that this application to NCI to supplement the research costs of this project was acceptable, and told to simply inform D.O.A. when she hears whether it will be funded.

Thus, the P.I. notified Patricia Modrow, MD, on August 4, 1999 that the RO3 application from NCI will likely be funded. This was noted by Dr. Modrow and I was informed just to note this development in the annual report.

2.3. Survey Development: Year two focused on the development of a survey to assess features of primary care which promote regular screening in Washington D.C. primary care clinics.

Based on the research questions of this project, a search for existing English questions was undertaken to benefit from previously validated and reliable survey items. If necessary, these survey items were re-worded as appropriate for our study population. Use of such prior work improved the quality of our instrument.

When items measuring topics raised in the focus groups from phase I could not be found, such as for particular priorities of low-income women for primary care, new items were developed. These items were reviewed by the P.I.'s mentors and pilot tested in English prior to translation for the Spanish version. Translation of these items into Spanish will be done by an experienced translator and community health educator from Columbia. The Spanish version of the survey will be piloted among Hispanic women and reviewed by a Hispanic senior health services researcher, Dr. Perez-Stable.

The main outcome variable of interest, utilization of breast cancer screening will be measured in several ways. The additional funding from NCI (RO3 described above) will also permit the survey to be lengthened to include cervical and colorectal cancer screening as well as the main focus of breast cancer screening. To this end, we hope to determine whether features of primary care which promote breast cancer screening are also associated with the receipt of regular cervical and colorectal cancer screening.

Use of “ever” and “recent” breast, cervical and colorectal cancer screening will be probed via previously validated items. (NHIS, etc.) Measurement of “regular” or adherent cancer screening over time presented much more complicated issues during the pilot phase. Numerous approaches to assess screening adherence were attempted including methods used by (Philips and Kerlikowske, Mandelblatt, Burnett, Kasper, Rakowski; as well as using items which the P.I. tried to develop). Any recollection of lifetime screening, or of screenings prior to the most recent test, were poor by most of the respondents. Attempts at measuring intention to get screened for breast cancer in the next year were made during piloting, but we felt that this variable could not be easily validated and given time pressures of the survey, we chose not to use an item measuring intent because its analytical usefulness was questionable.

Ultimately, for measurement of regular breast (clinical breast exam, mammogram) cervical (pap) and colorectal (fecal occult blood) screening utilization, we opted to include one item on total lifetime number of the test, and a second item which asks the women about her second to last test. (For age appropriate respondents we ask: 1)Whether she had a CBE, and a mammogram in the 2 years prior to the most recent test; 2)Whether she had a pap in the three years prior to the most recent one, and 3)Whether she had a fecal occult blood test in the two years prior to the most recent one.) We also decided to ask women in piloting about the age they were at their first screening test, and how often they had been screened since then. While less exact than obtaining the woman’s “best estimate” of total lifetime screening by expecting her to recall each screening test, this question on about how often she obtained the test seemed to be easier for the woman to recall.

For the items on cancer screening knowledge, attitudes and beliefs, items were chosen from a survey by Dr. Eliseo Perez-Stable et al, which had been previously translated into Spanish using highly refined translation techniques. In terms of beliefs for African-American women, we choose items from the recent study by Lannin et al (JAMA) after personal communication with the author and review of their instrument. In piloting, items which used terminology which was unclear to respondents were dropped in favor of items from Lannins’ survey which were less confusing.

Piloting of Survey

Earlier drafts of the telephone survey were piloted by the P.I. on a convenience sample of women from Washington, D.C. fitting the inclusion criteria of the study. The majority of these women were from the community health clinic, Zacchaeus Free Clinic in Washington, D.C. Piloting was done both in-person and by phone. The version of the survey included in this annual report is the one which results from revisions made during the piloting phase. A report summarizing the findings from the pilot phase is included in the appendix.

Telephone administration: Fielding of survey

In late fall/early winter of year three (Nov 1999-Jan 2000) the telephone survey will be fielded.

Setting and Population : Inclusion criteria for the survey are: being female, age over 40 years (will stratify sample to assure adequate numbers of women over age 50: Age 40-49, 50-64, 65 and over), speaking English or Spanish, having no history of breast cancer, residing in wards 1,2,5,6,7 or 8 of

the District (based on per capita incomes and poverty statistics), and living at 200% of poverty level or less.

It is estimated that there are 90,636 black women and 4,607 Hispanic women over age 40 living in the District of Columbia. (1990 U.S. Census for the District of Columbia, Summary Tape File 1). With regard to telephones: 95.8% (239,105) of all households in the District of Columbia have telephones; 93% of Hispanic households have telephones; and, 94% of black households have telephones. (1990 Census of Population and Housing, Census Bureau, Pub. No. CPH-3-331).

3.0. Data Collection: Based on the findings of the focus groups and on previously validated instruments, a telephone survey will be developed to collect more specific data on the features of primary care which promote regular breast, cervical, and colorectal cancer screening among low-income minority women in the District of Columbia. The proposed survey will collect data on the structure and process of primary care, including validated measures assessing it's the key components.

3.1 Recruitment of Sample: A list of randomly generated telephone numbers for selection of the sample, will be provided by Genesys Sampling Systems Corp. By merging phone listings from the residential white pages, and demographic information on gender, age and income from marketing data, the corporation can generate a reasonably efficient list of women aged over 40 living in the targeted wards of the District. Women over age 50 will be over-sampled to assure adequate numbers. A random-digit dial sample based on phone exchanges, targeted to the telephone exchanges of persons with the demographic characteristics and residence in the wards of interest, will supplement this list. The P.I. will work closely with Genesys Corp. in the development of this list of age and income eligible women to assure that it respects the inclusion criteria for survey participation. Distribution of the sample from each of the wards will reflect 1998 population statistics. Given the difficulty often experienced in recruiting members of high-risk populations a total of 600 telephone interviews will be completed.

A list containing 10,000 phone numbers will be generated under the assumption, based on prior work in this population,⁸⁹ that 10 phone numbers will need to be called to obtain each eligible respondent. The response rate is conservatively estimated at 60% (for this hard-to-reach group), and this would provide us with 600 completed interviews.

Completion of the 600 telephone surveys requires trained bilingual (Spanish-English) interviewers, Computer Assisted Telephone Bank (CATI), and several phones to complete the required interviews, as well as office space for the interviewers. For this reason the telephone phase of the survey will be contracted out. The survey will be completely designed by the P.I. and will be piloted initially by the P.I., on a SES-matched convenience sample of 20 women, to refine certain items and assess flow of the items. The P.I. will then give the survey and the list of phone numbers from Genesys Corp. to the telephone survey- corporation which will carry out administration of the telephone survey in the field. The contracting corporation (lowest cost estimate from Opinion Research Corporation) will re-pilot the survey in English and in Spanish. The P.I. will oversee the survey corp. in its conduction of the telephone phase. As stated in the original proposal, the P.I. will perform data quality assessment, all of the analyses on the data in SAS, including clean-up of

the data, variable definition (formatting) and all exploratory and statistical analyses; she will write manuscripts on findings and disseminate results. The P.I. has experience in SAS programming and survey data analysis and will work under the guidance of an experienced cancer prevention researcher, social scientist-cancer prevention researcher, and biostatistician.

3.2. Analysis : The original analysis plan and power calculations presented in the original proposal still apply. The only difference is the administration of the survey via telephone to a population based sample, rather than to a convenience sample from four clinics.

3.2.1 Power: Of the four screening tests which will be considered in this proposal, mammography has a low projected rate of regular use over time. For this reason, sample size calculations were conservatively based on projected "regular" mammography screening rates. Given the difficulty often experienced in recruiting members of high-risk populations a total of 600 telephone interviews will be completed. For analyses in which a dichotomous outcome variable is used (regular versus non-regular screening) this sample size will provide power of 80% at the .05 (one-sided test) significance level to detect differences of 10% or greater between screening groups (e.g., regularly and non-regularly screened women) assuming a baseline of 25% regularly screened for the most conservative screening rates.²⁷⁻²⁸ For analyses using a continuously scaled regular screening outcome variable, this sample of 600 women will provide more than adequate power.

4.0 Strengths and Limitations: Limitations of the project include the generalizability to persons without telephones and the lack of validation of self-report data. With regard to use of the telephone, it is estimated that 94% of African-American households and 93% of Hispanic households in the District of Columbia have phones. (1990 U.S. Census for D.C., STF1) Use of population-based personal interviews would not be feasible given the resources available for the project. It is possible that those least likely to have access to primary care and to cancer screening will also be those persons without telephones, thus barriers perceived by this particular subgroup may be understated. With regard to validation of reports on screening, self-report generally overestimates the prevalence of screening. Since this study involves a population-based sample, women will likely receive care from a variety of settings in Washington, D.C. Thus, validation of self-reports through medical record review will not be practical. Characteristics which might influence the validity of self-reports, such as education, socioeconomic status and acculturation will be controlled for in analyses.

Strengths include: 1) the population-based sampling which will provide information from those with little or no access to primary care, 2) the focus on an understudied group i.e. low-income minority women, 3) a sampling plan which reflects the demographic distribution of lower income women from throughout the District of Columbia, 4) prior work with focus groups to inform the development of the survey, 5) use of trained bilingual interviewers with CATI capability, 6) unique focus on the nature of features of primary care important to regular cancer screening from the perspective of women served, and 7) the mentoring and collaboration of experienced cancer control, primary care and behavioral researchers.

5.0. Dissemination and Future Research: Findings from this project will be presented at national scientific meetings including: the annual Department of Army Breast Cancer meeting in Atlanta in

June, 2000; and the Association of Health Services Researchers. In addition, findings will be presented to the community clinic directors (and their advisory boards) whose clinics allowed the P.I. to advertise for volunteers for the focus groups conducted in 1998. The project will also continue to be presented in its various stages at Georgetown University Medical Center in various forums such as the Division of Cancer Control and Prevention's research seminars.

6.0. Implications of project for future study: Based on survey findings, a primary care intervention to address the specific mutable aspects of primary care as they relate to cancer screening will be developed in the future. (This will be the subject of a future proposal) Together, such research has the potential to decrease the disproportionate cancer burden experienced by lower-income Black and Hispanic women.

7.0. Confidentiality and Security : All data will be stripped of personal identifiers in the database and assigned a respondent I.D. number. Data will be maintained electronically via entry from a CATI system and this data will be kept secure by the P.I. and by the contracting telephone survey corporation. All information provided by respondents will be confidential, no attempts will be made to link respondents to any other databases. Permission to move from a written to verbal consent has already been obtained by the Dept of Army and by the Georgetown University IRB. The survey has also been approved by the IRB.

8.0 Coursework

The P.I. pursued a self-guided study of research design under the guidance of her mentors. This included reading the texts: *Designing and Conducting Health Surveys* by Lu Ann Aday, and *Primary Care*, 2nd ed, by Barbara Starfield. The first text reviewed the planning, development and analysis of survey instruments and their data. The text on *Primary Care*, focused on the conceptual framework of primary care and the measurement of its attributes. Dr. Starfield's *Primary Care Assessment Tool* described in this text is one of the measures which will be used in this telephone survey to assess attainment of attributes of primary care and whether such attainment is associated with regular breast cancer screening.

The P.I. will also enroll in a course on the design and conduct of clinical trials will be taught at Johns Hopkins School of Public Health's Satellite campus in Montgomery county from March 29, 2000 to May 21 2000. This course will help to lay the foundation for the P.I.'s planning of a proposal for a clinical trial to test an intervention in the primary care setting that promotes regular breast cancer screening. (Year 4)

9.0. Meetings attended

Prevention99: American College of Preventive Medicine's annual national meeting. Presented poster on Health Information Sources Used by a Multi-ethnic community. This project was a secondary data analysis of the NYC multiethnic dataset which the P.I. analyzed in years 1 and 2 of this DOA award. The poster won the prize for the best poster. (See appendix for documentation)

In addition, the P.I. met on a tri-weekly basis with her primary mentor, Dr. Jeanne Mandelblatt to discuss all phases of the project and its development.

The P.I. attended journal club in the Division of Cancer Prevention and Control, Lombardi Cancer Center, Georgetown University. She prepared a presentation for one of the sessions as well on an article on cancer screening.

10.0 Manuscripts from Year 2:

10.1 Additional Secondary Analysis of Multiethnic NYC Data: The P.I. performed another secondary analysis of this NYC multiethnic data. From these analyses resulted a manuscript entitled: "Are We Getting the Message Out to All? Health Information Sources and Ethnicity." This manuscript described the health and cancer information channels used by the largest Black and Hispanic ethnic groups in NYC. It was accepted for publication by the *American Journal of Preventive Medicine*. It will appear in the November, 1999 issue of the journal. (Manuscript included in appendix.)

10.2 Paper Resulting from the Phase I (Year 1) Focus Groups: As mentioned in the first annual report, the focus groups were very successful and well received by the participants who provided us with very rich qualitative information on their use of primary care and breast cancer screening services in the primary care setting. A summary report of the focus groups, as well as a synopsis of the results were presented in last year's annual report. During year two, the P.I. continued to analyze the focus group transcripts with the goal of informing the survey to be developed in phase II. The focus group findings were submitted in part for publication to the *Journal of Family Practice*. The reviewer's comments were received and the paper was revised and resubmitted. A copy of this paper is included in the appendix of this second annual report.

10.3 Manuscript written in year one, published in year 2 in the American Journal of Public Health: An article on acculturation of Latinas and breast cancer screening was done as a result of analysis of the NYC multiethnic data. This is also included in the appendix.

APPENDICES

Key Research Accomplishments

Year One

- Completed Several analyses of the New York City Multiethnic Data set on Cancer Screening
- Published Paper in the American Journal of Public Health on Acculturation and Breast Cancer Screening in Hispanic Women as a result of one of these analyses of NYC data
- Developed models that to assess features of primary care that were associated with use of CBE and mammography as reported in the first annual report and in the above publication in American Journal of Public Health (submitted in year one annual report)
- Contacted directors of community clinics in Washington D.C. and conducted in-depth interviews of directors as well as visited their clinics
- Conducted four focus groups of Hispanic and African-American Women from four community health clinics in Washington D.C. to probe their experiences with cancer screening and with primary care
- Wrote report summarizing focus group findings (submitted in year one annual report)
- Abstract submitted to the Society of General Internal Medicine's Annual Meeting

Year Two

- Developed survey to collect data from women in Washington, D.C. to obtain their experiences with breast cancer screening, as well as cervical and colorectal cancer screening, in their primary care settings
- Obtained additional funding from NCI in the form of a small research grant (RO3) which will help to pay for the telephone administration of the survey and allow expansion of the survey to include cervical and colorectal cancer in addition to the focus of breast cancer
- Piloted the survey among women meeting inclusion criteria from a community clinic in Washington, D.C.
- Wrote summary report of survey pilot findings (in appendix)
- Began sample identification with the corporation which will generate the phone list of targeted random-digit-dial numbers
- Presented research study on health and cancer information sources used by a multiethnic community in NYC as a result of further analyses of multiethnic data from phase one

- Submitted and had accepted a manuscript resulting from analysis of the NYC multiethnic data on “Health and cancer information sources used in a multiethnic population,” American Journal of Preventive Medicine (in appendix)
- Submitted a manuscript of focus group findings (from year one) to the Journal of Family Practice, which is under review. (in appendix)

Reportable Outcomes

1. Manuscripts

O'Malley AS, Mandelblatt J, Johnson A, Kerner J. "Acculturation and Use of Breast Cancer Screening in Urban Hispanic Women." *American Journal of Public Health*. 1999;89:219-227.

O'Malley AS, Kerner J, Johnson L. Are We Getting the Message Out to All? Health Information Sources and Ethnicity. *American Journal of Preventive Medicine*. 1999;17 (3) In press.

O'Malley AS, Forrest CB, O'Malley PG. Low Income Women's Priorities for Primary Care. *Journal of Family Practice*. 1999. Revision under review.

Mandelblatt J, Gold K, **O'Malley AS**, Taylor K, Cagney K, Hopkins JS, Kerner J. "Use of Breast and Cervix Cancer Screening by Multi-Ethnic Elderly Women." *Preventive Medicine*. 1999; April 28 (4):418-425.

2. Abstracts

O'Malley AS, Kerner J, Johnson L. Are We Getting the Message Out to All? Health Information Sources and Ethnicity. Prevention99: American College of Physician's Annual Meeting.

3. Presentations

O'Malley AS, Kerner J, Johnson L. Are We Getting the Message Out to All? Health Information Sources and Ethnicity. Prevention99: American College of Physician's Annual Meeting.

4. Awards

Best Faculty Poster Award at the American College of Preventive Medicine's and American Teacher's of Preventive Medicine's annual meeting, *PREVENTION 99*
For: **O'Malley AS**, Kerner J, Johnson L. Are We Getting the Message Out to All? Health Information Sources and Ethnicity. Prevention99: American College of Physician's Annual Meeting.

5. Funding Obtained based on Work Supported by this Award

NCI-RO3. August 1999-December 2001. (Principal Investigator) Community-Based Primary Care and Regular Cervical, Colorectal and Breast Cancer Screening in Low-Income Women. (Explained in detail in the above annual report.)

Summary of Findings from the Piloting of the Survey:

Various drafts of the survey were piloted both by phone and in-person, during its development. The latest draft was piloted on a convenience sample of 15 women who met inclusion criteria for the study. Most of these women were from the Zacchaeus Free Clinic in Washington, D.C. and these final pilot interviews were done in person in the clinic waiting room by the P.I.

I. Length of Interview

Early drafts of the interview were too long as expected, lasting almost one hour. Numerous items on cancer screening, primary care and health status were cut to decrease the length. Currently the interview administration takes 30 minutes, including screener questions. For women who are not Hispanic and don't have to answer the acculturation questions, and for women under age 50 who don't qualify for colorectal cancer screening, the interview takes even less time.

II. Response Formats

Response formats range from 2-category (Yes/No) responses, to 5 point Likert Scaled responses, to scales which ask the respondent to rate on a scale from 0 to 10 where 0 is very poor and 10 is very good. In order to preserve the scaling properties of previously validated scales such as the Primary Care Assessment Survey (DG Safran, et al.) it is necessary to keep the response formats as they are in the original scale. This not only enhances validity but will allow comparisons between this study population and other national data which use the same instrument to measure attributes of primary care.

(Personal conversation with DG Safran, June 1999) The P.I. was concerned that the 5 and 6 category responses might be overwhelming for lower literary respondents. During piloting, it was found that as long as responses are read to the respondent after each question, she is well able to use the 5 or 6 category response format. The 0 to 10 response scale (very poor=0 and very good=10) was not a problem for respondents in this pilot phase.

III. Item Wording/Literacy level compatibility

Some words from items were replaced with simpler terminology. The literary level of the final survey will be checked by a health educator here at Lombardi prior to the final fielding the survey.

IV. Content Areas

Cancer Screening Utilization

Use of "ever" and "recent" breast, cervical and colorectal cancer screening will be probed via previously validated items. (NHIS, etc.) Measurement of "regular" or adherent cancer screening over time presented much more complicated issues during the pilot phase. Numerous approaches to assess screening adherence were attempted including methods used by (Philips and Kerlikowske, Mandelblatt, Burnett, Kasper, Rakowski; as well as using items which the P.I. tried to develop). Any recollection of lifetime screening, or of screenings prior to the most recent test, were poor by most of the respondents. Attempts at measuring intention to get screened for breast cancer in the next year were made during piloting, but we felt that this variable could not be

easily validated and given time pressures of the survey, we chose not to use an item measuring intent because its analytical usefulness was questionable.

Ultimately, for measurement of regular breast (clinical breast exam, mammogram) cervical (pap) and colorectal (fecal occult blood) screening utilization, we opted to include one item on total lifetime number of the test, and a second item which asks the women about her second to last test. (For age appropriate respondents we ask: 1) Whether she had a CBE, and a mammogram in the 2 years prior to the most recent test; 2) Whether she had a pap in the three years prior to the most recent one, and 3) Whether she had a fecal occult blood test in the two years prior to the most recent one.) We also decided to ask women in piloting about the age they were at their first screening test, and how often they had been screened since then. While less exact than obtaining the woman's "best estimate" of total lifetime screening by expecting her to recall each screening test, this question on about how often she obtained the test seemed to be easier for the woman to recall.

Cancer Attitudes/Beliefs

We choose items from the recent study by Lannin et al (JAMA) after personal communication with the author and review of their instrument. In piloting, items which used terminology which was unclear to respondents were dropped in favor of items from Lannin's survey which were less confusing.

Health Status

The SF-12 (Medical Outcomes Study) was chosen. It was clearly understood by all respondents during piloting. The only adjustment that was made was to read the responses after each item for the respondents.

Primary Care

We opted for use of the **Primary Care Assessment Survey** (PCAS, Safran et al) scale to measure the main attributes of primary care, because of its understandability during piloting and because it measures the attributes of primary care which are most relevant to our research questions and to the priorities of women from the focus groups (done during year one.) Other items measuring primary care were considered and piloted. The sources of these items were:

The **National Association of Community Health Centers' (PEERS) Patient Experience Evaluation Report System**, supported by the Commonwealth Fund, is a survey developed especially for work with the populations served by community health centers.⁷³ The questionnaire has been vigorously field tested and is a reliable tool to measure use of community health services in poor patients in medically under-served areas. Available in many languages, including Spanish, it takes into careful account the literacy level and cultural needs of the persons served. Items from this questionnaire will be used to query respondents on the domain of accessibility as well as their use of medical services, including their usual source of care, type of clinician treating them, reasons for choosing those particular provider(s), preferences for types of providers and other aspects of the structure and process of ambulatory care.

The **Primary Care Assessment Survey (PCAS)** is a validated questionnaire designed to measure specific aspects of accessibility (organizational and financial), continuity, comprehensiveness and the patient-provider relationship (communication, interpersonal treatment, trust).⁷⁴ All concepts are measured in the context of the global primary care relationship, the items are not visit specific.

The **Consumer Primary Care Survey** developed by researchers at Johns Hopkins⁷⁵ has been used on a low-income population of children and care-givers in ward 6 of the District of Columbia. It has several validated items measuring accessibility, comprehensiveness, continuity, and coordination. Since the P.I. will be working with the developers of this survey as consultants to the project, they will advise her on the best way to validate this measure in adult women and to modify the items as necessary for work with adults.

The **Components of Primary Care Index (CPCI)**⁴⁸, is a brief and reliable measure of four important aspects of the delivery of primary care: communication (part of the patient-provider relationship), physician's knowledge of the patient (patients perception of accountability and an aspect of continuity), coordination of care, and the patients preference to see their regular physician (important to measuring importance respondents place on continuity with a specific provider).

The **Consumer Assessment of Health Plans (CAHPS)** survey, developed for the Agency for Health Care Policy and Research by the Research Triangle Institute and by RAND Corporation, assesses consumer's assessments and impressions of their health care.⁷⁶ It has specific components for Medicaid enrollees, and is also available in Spanish. Items on this survey which apply to Medicaid populations were developed and tested via focus groups by RAND.⁷⁷

In addition, numerous stages of questions were piloted to probe what women felt was most important about primary care based on the focus group findings. Items which asked the women the rank the features of primary care according to how important they were to the woman were assessed in several ways including likert-scaled and 0 to 10 scaled responses. However, almost universally, regardless of how the items were worded, women ranked all features which were found to be important in the focus groups, as being very important. This resulted in a skewed distribution of responses with little variability. Therefore in the interest of minimizing the length of the survey and avoiding items which would yield little information (given low variability among responses in piloting) these items which asked women to rank their priorities were dropped.

In an attempt to try to identify the type of physician seen as the regular doctor, pilot respondents were asked what type of doctor they saw at their usual source of care. However, most women were not able to identify the type of primary care physician they saw (internist, family practitioner, general practitioner or other type) so the question which tried to identify type of primary care doctor was dropped.

Demographics

Items on demographics were taken mostly from previously validated surveys. Some were modified for use in this lower literacy population. All items were easily understood by the pilot respondents.

V. Item flow

The flow was revised in various ways as a result of piloting. For example, the question on ethnic identification was moved in front of the acculturation scale, so that Hispanic respondents could be identified before proceeding with the acculturation scale (which would be done only in Hispanics). Other order changes included putting more personal questions (income) at the end of the interview. Identifying information which would ensure that inclusion criteria are met (such as age) were moved to the front of the interview. Cancer screening questions are placed in the front of the interview after the section on health status which is likely to be less threatening to the respondent.

Telephone Survey

Primary Care and Regular Breast Cancer Screening in Under-Served Minority Women in Washington, D.C.

DAMD17-97-1-7131

Ann S. O'Malley
202-687-0862 (phone)
202-687-5229 (fax)

ITEM	SOURCE	RESPONSE
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1. Interview Date:		__ / __ / __
2. Respondent ID Number:		_____
3. Interviewer:		-----
4. Respondent phone number: (FROM LIST, DO NOT ASK)		(202) ____ - ____
5. Source of number		1 Random digit dial targeted exchange 2 Residential listing randomly chosen

IF PHONE IS ANSWERED BY "BUENO", "DIGA", OR "ALO" GO TO SPANISH VERSION:

Hello, my name is _____. I am calling from Opinion Research Corporation. Your phone number was selected at random as part of study of women's health in Washington, D.C.

<p>6. May I please speak to the women who lives at this address who is <u>41 years old or older</u> ?</p> <p>IF PERSON WHO ANSWERS THE PHONE VOLUNTEERS THAT THERE IS MORE THAN ONE WOMAN OVER AGE 40 PRESENT IN THE HOUSEHOLD, ASK TO SPEAK TO THE ONE WITH THE MOST RECENT BIRTHDAY: May I speak to the women age 41 or over who had the most recent birthday?</p>	<p>1 <input type="checkbox"/> Yes (GO TO 8)</p> <p>2 <input type="checkbox"/> Other respondent called to phone (REINTRO THEN GO TO 8)</p> <p>3 <input type="checkbox"/> Not available (GO TO 7)</p> <p>4 <input type="checkbox"/> Refused (GO TO 7)</p>
<p>7. What would be best time to call back?</p> <p>When we call you back, would you prefer that we do so in English or in Spanish?</p>	<p>Date: _____</p> <p>Time: _____ am _____ pm</p> <p>English _____</p> <p>Spanish _____</p>

8. We would like you to tell us about your experiences with health care so that the health care system can be improved to better meet the needs of women like you. Your answers will be kept completely confidential and will never be tied to your name.		
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9. IF PERSON IS HAVING DIFFICULTY UNDERSTANDING ENGLISH ASK: Would you prefer that we conduct this interview in English or Spanish?		1 <input type="checkbox"/> English 2 <input type="checkbox"/> Spanish -RESTATE PARAGRAPH 7D IN SPANISH AND PROCEED WITH SPANISH QUESTIONNAIRE
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The interview should take twenty-five minutes. You are free to refuse to answer any questions or stop the interview at any time. Any questions before we begin?

PROMPTS ONLY IF QUESTIONS:

FUNDING:

This study is being led by Georgetown University Medical Center in Washington, DC and is funded by the Department of Defense and the National Cancer Institute.

CONFIDENTIALITY:

All of your responses are confidential. Your answers will never be shared with insurance companies. Your name or other identifying information will never be linked with your answers. Your name will never be used or shared in any way. Your answers are grouped anonymously with those of other women and used for the purposes of the study only.

PURPOSE OF THE STUDY:

This is a telephone survey which asks about your experiences with health care and about your health. The information will be used to try to improve the health care system for women such as yourself.

HOW LONG WILL THIS TAKE:

It depends on your answers. On average, the interview takes about 25 minutes.

DO I HAVE TO ANSWER ALL OF THE QUESTIONS?

You are free to refuse to answer any questions or to stop the interview at any time. There are no right or wrong answers to the questions. We are interested in your opinions and experiences.

WHO CAN I CALL TO MAKE SURE THIS IS A LEGITIMATE STUDY?

Ann O'Malley at 202-687-0862

HOW DID YOU GET MY NUMBER?

It was chosen at random by a computer.

May we begin the interview?

ALL CASES:

I am going to read you a set of questions exactly as they are worded. Everyone taking this survey is asked the same questions. For most questions, I will read you a list of answers to choose from.

<p>10. IF REFUSES:</p> <p>Reasons for Refusal:</p>	<p>1 <input type="checkbox"/> Too busy (ARRANGE FOR CALL BACK)</p> <p>2 <input type="checkbox"/> Information sensitive (ASSURE CONFIDENTIALITY)</p> <p>3 <input type="checkbox"/> Respondent incapacitated (Hearing/speech)</p> <p>4 <input type="checkbox"/> Concern about confidentiality (PROMPT ON CONFIDENTIALITY)</p> <p>5 <input type="checkbox"/> Concern about safety (PROMPT ON SAFETY)</p> <p>6 <input type="checkbox"/> Other (Specify)</p>
<p>INTERVIEWER: CODE THE LANGUAGE USED FOR THE INTERVIEW</p>	<p>1 English</p> <p>2 Spanish</p>
<p>I'm going to begin by asking you some general questions about you and your health.</p>	
<p>11. Can you please tell me how old you are ?</p> <p>(AS OF LAST BIRTHDAY)</p>	<p>_____ (years of age)</p> <p>(IF UNDER 41 END INTERVIEW BY SAYING: WE CAN ONLY INTERVIEW WOMEN AGE 41 AND OVER, THANK YOU FOR YOUR TIME)</p> <p>2 <input type="checkbox"/> DK</p> <p>3 <input type="checkbox"/> REF</p>

12. What is the highest grade in school you have completed? (PLEASE CIRCLE THE GRADE.)	<div> Grade School Junior High/High School 1 2 3 4 5 6 7 8 9 10 11 12 College 13 14 15 16 17+ 18 (GED-High school Equivalency degree) 19 DON'T KNOW 20 REF </div>
13. Are you <u>currently</u> married?	<div> 1 Yes 2 No (includes divorced, widowed, single, separated) 3 DON'T KNOW 4 REF </div>

HEALTH STATUS (CHECK ON SCORING OF RESPONSES)

(Source of Questions Rand, SF-12)

ITEM	SOURCE/NOTES	RESPONSES		
14. In general, would you say your health is....? (READ RESPONSES)	MOS item #1, SF-12 Permission obtained from JE. Ware, Aug 1999 (Junius has the scoring manual)	1 <input type="checkbox"/> Excellent 2 <input type="checkbox"/> Very Good 3 <input type="checkbox"/> Good 4 <input type="checkbox"/> Fair 5 <input type="checkbox"/> Poor		
The following questions are about activities you might do during a typical day.	SF-12			
(READ RESPONSES)	SF-12	Yes, Limited a Lot 1	Yes, Limited a Little 2	No, Not limited At All 3
15. Does your <u>health</u> now limit you in <u>moderate activities</u> , such as moving a table, or pushing a vacuum cleaner? (USE TWO STAGES TO DETERMINE RESPONSE: FIRST AS YES/NO, THEN IF RESPONDS YES ASK WHETHER LIMITS A LOT OR A LITTLE)	Item #2a	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Does your health now limit you in climbing <u>several flights</u> of stairs?	Item #2b	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. During the <u>past four weeks</u> have you <u>Accomplished less</u> than you would like as a result of your physical health?	SF-12 Item #3a	1 Yes 2 No		
18. During the past four weeks, were you limited in the <u>kind</u> of work or other activities as a result of your physical health?	SF-12 Item #3b	1 Yes 2 No		
19. During the past four weeks, have you accomplished less than you would like as a result of any <u>emotional</u> problems? (such as feeling depressed or anxious)	SF-12 Item #4a	1 Yes 2 No		

20. During the past four weeks did you do work or other activities less carefully than usual as a result of any <u>emotional</u> problems?	SF-12 Item #4b	1 Yes 2 No
21. During the past 4 weeks, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)? (READ RESPONSES)	SF-12 Item #5	1 Not at all 2 A little bit 3 Moderately 4 Quite a bit 5 Extremely

The next questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. I will read the answers to you.

SF-12

All of the Time	Most of the Time	A Good Bit of the time	Some of the Time	A Little of the Time	None of the Time
1	2	3	4	5	6

22. During the past four weeks, how much of the time have you felt calm and peaceful? Would you say...
(READ RESPONSES)

SF-12
Item 6a

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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23. How much of the time during the past four weeks, did you have a lot of energy?

SF-12
Item 6b

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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24. How much of the time during the past four weeks, have you felt down hearted and blue?

SF-12
Item 6c

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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25. During the past 4 weeks, how much of the time have your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

SF-12
Item #7

All of the Time	Most of the Time	Some of the Time	A Little of the Time	None of the Time
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Now I'd like to ask you some questions about tests for cancer:

CANCER EXPERIENCE

26. Have you ever been told by a doctor that you had breast cancer?	If respondent answers yes to this item, I will need to exclude her from certain analyses.	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No 3 <input type="checkbox"/> Don't Know 4 <input type="checkbox"/> Ref
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SCREENING UTILIZATION

PAP SMEAR		
<p>A pap smear is a test in which you lie on a table with your feet in the stirrups, and the doctor or nurse examines the female internal organs by taking a swab of the cervix and sending a cell sample to the lab.</p> <p>27. Have you ever had a pap smear?</p>	NHIS	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No (GO TO NEXT SECTION LEAD-IN TO QUES #33) 3 <input type="checkbox"/> DON'T KNOW 4 <input type="checkbox"/> REF
<p>28. When did you have your most recent pap smear?</p>	NHIS	1 <input type="checkbox"/> 1 year ago or less (in the past 12 months) 2 <input type="checkbox"/> Between 1 to 2 years ago (> 12 months, <=24 months) 3 <input type="checkbox"/> Between 2 to 3 years ago (>24 months, <=36 months) 4 <input type="checkbox"/> More than 3 years ago 5 <input type="checkbox"/> DON'T KNOW 6 <input type="checkbox"/> REF
<p>29. Did you have a pap smear during the three years before this most recent one?</p>		_____ (years)
<p>30. How old were you when you had your very first pap smear?</p>		_____ (years)

31. How often have you been getting pap smears?		1 Every 6 months 2 Every year 3 Every two years 4 Every three years 5 Every four years 6 Every five years 7 Have not been getting regular pap smears
32. How many pap smears total would you say you've had in your lifetime?		1 ----- (IF KNOWS, ENTER TOTAL NUMBER, OTHERWISE, READ RESPONSES) 2 <5 3 5-9 4 Between 10 and 15 5 Between 16 and 20 6 More than 20 7 DON'T KNOW

CLINICAL BREAST EXAM:

33. Now I'm going to ask you about breast physical exams.		
A breast physical exam is when the breast is felt for lumps by a doctor or nurse. 33. Have you <u>ever</u> had a breast physical exam by a doctor, nurse or medical assistant?	NHIS	1 Yes 2 No (RE-READ DEFINITION AND THEN SAY, "This is different from a mammogram" IF STILL ANSWERS 'NO' THEN SKIP TO NEXT SECTION, LEAD-IN TO QUESTION #39) 3 DON'T KNOW 4 REF
34. When was your <u>most recent</u> breast physical exam by a doctor, nurse or medical assistant?	NHIS	1 1 year ago or less 2 Between 1 to 2 years ago(> 12 months & <=24 months) 3 Between 2 to 3 years ago (>24 months, <=36 months) 4 More than 3 years ago 5 DON'T KNOW 6 REF

35. Did you have a breast exam by a doctor or nurse <u>during the two years</u> before this most recent one?		1 Yes 2 No
36. How old were you when you had your very first <u>breast</u> physical exam?		_____(years)
37. How often have you been getting <u>breast</u> physical exams ?		1 Every 6 months 2 Every year 3 Every two years 4 Every three years 5 Every four years 6 Every five years 7 Have not been getting regular breast physical exams
38. How many breast physical exams <u>total</u> would you say you've had in your <u>lifetime</u>?		----- (enter total number) 2 DON'T KNOW 3 REF

MAMMOGRAM:

39. Now I'm going to ask you about mammograms		
A mammogram is an X-ray taken of the breast by a machine that presses the breast flat. It is not a chest X-ray like you would have for pneumonia. This X-ray takes a picture to check for early breast cancer.		
39. Have you <u>ever</u> had a mammogram?	NHIS	1 Yes 2 No- (SKIP TO NEXT SECTION, #48) 3 DON'T KNOW/NOT SURE 4 REF--
40. When was your <u>most recent</u> mammogram?	NHIS	1 1-2 years ago 2 greater than 2 but less than 3 years ago 3 more than 3 years ago
41. Did you go for your last mammogram because of a lump or specific breast problem, or for a routine checkup?		1 Routine checkup 2 Health related reason

<p>42. What is the name of the place where this mammogram was done?</p> <p>(IF RESPONDENT DOESN'T VOLUNTEER NAME, THEN READ HER THE LIST)</p>	<p>Will use for validation of self-report of screening mammography</p>	<p>1 Betty Ford Breast Center 2 Columbia Hospital for Women 3 DC General Hospital 4 DC Chartered Health 5 George Washington Univ Hospital 6 George Washington Mobile Mammography Program 7 Georgetown University Radiology Assoc. at Foxhall Square 8 Georgetown University Medical Center 9 Greater Southeast Community Hospital 10 Hadley Memorial Hospital 11 Health South Diagnostic Center, (Metropolitan Mammography) 12 Howard University Hospital/Cancer Center 13 Kaiser Permanente 14 Office of Medical Services 15 Project WISH 16 Providence Hospital (Wellness Institute) 17 Sibley Memorial Hospital 18 Union Medical Center 19 The Washington Clinic, Chartered 20 Washington Hospital Center (Hospital Center) 21 Washington Radiology Associates 22 Women's Center for Breast Diagnosis 23 Yater Medical Group 24 Other 25 DK/REF</p>
<p>43. Did you get another mammogram during the two years before this most recent mammogram?</p>		<p>_____ (years)</p>

44. How old were you when you had your very first mammogram?		_____(years)
45. How often have you been getting mammograms ?		1 Every 6 months 2 Every year 3 Every two years 4 Every three years 5 Every four years 6 Every five years 7 Have not been getting regular mammograms
46. How many mammograms <u>total</u> would you say you've had in your <u>lifetime</u>?		----- (enter total number) 2 DON'T KNOW 3 REF
47. Did your doctor ever order or recommend that you get a mammogram?		1 Yes 2 No 3 DON'T KNOW/NOT SURE 4 REF

COLON CANCER SCREENING		
(IF WOMAN IS UNDER AGE 50 SKIP TO ITEM 54)		
48. Now I want to ask you about a test for colon cancer. This is the blood stool test.	NHIS terminol ogy	
<p>The blood stool test checks for blood that one cannot see in the stools or bowel movement. There are two ways this may be done. First, a doctor or nurse wearing a glove, puts a finger in the rectum and gets a stool sample and it is put on a small slide.</p> <p>Or, instead, you can take samples from your stool, yourself after going to the bathroom. This is done for three days. You put the samples on small cards provided by a doctor and return them for testing.</p> <p>48. Have you ever had a blood stool test?</p> <p>(PROMT IF NECESSARY: Put stool samples on cards yourself, or have you ever had it done by a doctor or nurse in a clinic or doctor's office?)</p>	NHIS	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No (SKIP TO) 3 <input type="checkbox"/> DON'T KNOW 4 <input type="checkbox"/> REF

49. When was your most recent blood stool test? (READ RESPONSES, BUT DO NOT READ THE WORDS IN PARENTHESES, THESE ARE JUST TO HELP INTERVIEWER WITH CODING)	NHIS	1 <input type="checkbox"/> 1 year ago or less 2 <input type="checkbox"/> Between 1 to 2 years ago (> 12 months & <=24 months) 3 <input type="checkbox"/> Between 2 to 3 years ago (>24 months, <=36 months) 4 <input type="checkbox"/> More than 3 years ago 5 <input type="checkbox"/> DON'T KNOW 6 <input type="checkbox"/> REF
50. Did you have a blood stool test during the two years before this most recent one?		_____ (years)
51. How old were you when you had your very first <u>blood stool test</u>?		_____ (years)
52. How often have you been getting blood stool tests ?		1 Every 6 months 2 Every year 3 Every two years 4 Every three years 5 Every four years 6 Every five years 7 Have not been getting regular stool tests
53. How many blood stool tests total would you say you've had in your lifetime?		----- (enter total number) 2 DON'T KNOW 3 REF

PRIMARY CARE MEASURES

Now I'm going to ask you questions about where you go for health care:

54. Is there one particular doctor/ or place that you go if you are sick or need advice about your health?	Permission to use PCAS Obtained June 1999 PCAS (Safran et al.) Item #1	1 Yes (GO TO 56) 2 No (GO TO 55)
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55. Is there a place where you go most often if you are sick or need advice about your health?	NHIS Use this for the reg source of care for those who answer 'no' to the previous question.	1 Yes (PROCEED WITH ENTIRE SECTION) 2 No (Skip to #118)
56. Can you tell me the name and address of (Doctor/Place P) ? (RIGHT DOWN NAME AND TRY TO GET INFO ON ADDRESS, IF RESPONDENT DOESN'T KNOW ADDRESS, AT LEAST GET INFO ON LOCATION)	PCAT – USOC Consider doing a survey of selected providers later on?	NAME _____ ADDRESS _____ _____ _____ _____
57. Is this a private doctor, an HMO, a health clinic, a hospital clinic a hospital emergency room, or some other type of site?	NHIS, 1992 Useful for subanalyses by type of usual site of care	1 Private Doctor's Office 2 HMO (Health Maintenance Organization) 3 Charter Health (Medicaid HMO) 4 Health Clinic 5 Community Health Center 6 Hospital Outpatient Clinic 7 Hospital Emergency Room 8 PPO (Preferred Provider Organization) 9 Other
58. How many times have you been to this clinic/doctor/place in the last 12 months?	Source: Jeanne and Ann to get a look at missed opportunities for screening	_____ (ENTER NUMBER)
59. How long has this (person/place) been your doctor/source of care? (SUBSTITUTE THE WORD PLACE IF ANSWERED YES TO QUES 2 OR 3)	PCAS Item #2 Continuity/Longitudinality	1 Less than 6 months 2 Between 6 months and 1 year 3 1 to 2 years 4 3 to 5 years 5 More than 5 years
60. Is this the person/place you call when you have a medical problem or question?	PCAS Item #3 Use this to assess first-contact care?	1 Yes 2 No

The next questions are about care you have received from the doctor you think of as your <u>regular</u> doctor.		
61. How would you rate the convenience of your regular doctor's office <u>location</u>? Is it... (READ RESPONSES)	PCAS Item 7b modified by AO after discussion with D Safran by phone on July 12, 1999	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
62. How would you rate the hours that your doctor's office/place is open for medical appointments? (READ RESPONSES)	PCAS 8b	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
63. How would you rate the usual <u>wait</u> for an appointment when you are sick and call the doctor's office asking <u>to be seen</u>? (READ RESPONSES)	PCAS 9b	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
64. How would you rate the amount of money you pay for doctor visits? (READ RESPONSES)	PCAS 11b	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
65. How would you rate the amount of money you pay for medication and other prescribed treatments? (READ RESPONSES)	PCAS 12b	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
Thinking about the times you have needed to see or talk to your doctor...		

66. How would you rate, the ability to get through to the doctor's office by phone? (READ RESPONSES)	PCAS 13a	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
67. How would you rate, the ability to speak to your doctor by phone when you have a question or need medical advice? (READ RESPONSES)	PCAS 13b	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
68. When you go for a <u>check-up or routine care</u> , how often do you see your regular doctor (not an assistant or partner)? (READ RESPONSES)	PCAS 14a	1 Always 2 Almost always 3 A lot of the time 4 Some of the time 5 Almost never 6 Never
69. When you are <u>sick</u> and go to the doctor, how often do you see your regular doctor (not an assistant or partner)? (READ RESPONSES)	PCAS 15a	1 Always 2 Almost always 3 A lot of the time 4 Some of the time 5 Almost never 6 Never
70. How would you rate the thoroughness of your doctor's physical examination of you to check a health problem you have? (READ RESPONSES)	PCAS 16a	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent

<p>I'm going to read you a list of things that you may have had done by your regular doctor or nurse or by someone in your regular doctor's office/clinic:</p> <p>Has your regular doctor or nurse or an assistant ever: (REPEAT FOR EACH ITEM)</p>	<p>Source: AO modified PCAS, but used same response options for scaling purposes. Replaces PCAS Items 21a-g</p> <p>Based on recommendations of the USPSTF 1996</p> <p>(Can be used to calculate comprehensiveness score, can also be used in separate analyses of self-reported adherence to preventive interventions)</p>	
<p>71. Checked your blood pressure (IF ANSWERS 'YES' QUERY AS TO WHETHER WAS IT WAS DONE IN THE LAST 3 YEARS, OR MORE THAN 3 YEARS AGO)</p>	<p>Screening Comprehensiveness</p>	<p>1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No</p>
<p>72. Checked your height and weight</p>	<p>Screening Comprehensiveness</p>	<p>1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No</p>
<p>73. Checked your cholesterol</p>	<p>Screening (Only recommended for women age 45 and over) Comprehensiveness</p>	<p>1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No</p>
<p>74. Talked with you about smoking</p>	<p>(Counseling) Comprehensiveness</p>	<p>1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No</p>
<p>75. Talked with you about Alcohol/Drinking?</p>	<p>Screening Comprehensiveness</p>	<p>1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No</p>
<p>76. Talked with you about your diet?</p>	<p>(Counseling) Comprehensiveness</p>	<p>1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No</p>
<p>77. Talked with you about getting enough calcium in your diet?</p>	<p>(Counseling) Comprehensiveness</p>	<p>1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No</p>

78. Talked with you about your mood or about times when you have felt down-hearted or blue?	(Use for psych analyses- Also for comprehensiveness)	1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No
79. Has your regular doctor/(place) ever talked with you about feeling nervous or anxious?	Use for psych analyses	1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No
80. Has your regular doctor ever told you that you were depressed?	Use for psych analyses	1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No
81. Has your regular doctor ever treated you with medication for being depressed ?	Use for psych analyses	1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No
82. Has your doctor ever suggested that you see a specialist for counseling for emotional concerns?		1 Yes, in the last 3 years 2 Yes, more than 3 years ago 3 Yes, I don't remember when 4 No
83. Does the doctor or nurse at (Place/Clinic) know about the important health problems of your neighborhood like crime, drugs or AIDS?	Starfield, PCAT- R3 Culturally Competent Care	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No
84. Would you recommend your (doctor/clinic) to someone who does not speak English well? (I.E. CONSIDER THE PRACTICE TO BE ACCESSIBLE TO..)	Starfield, PCAT- H1 Culturally Competent Care Language accessibility	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No

Provider-Patient relationship

85. Thinking about <u>talking with your regular doctor</u> , how would you rate the following:	PPR communication	
85. How would you rate the thoroughness of your doctor's <u>questions</u> about your symptoms and how you are feeling, is it... (READ RESPONSES AFTER EACH QUESTION)	PCAS 17a PPR communication	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
86. How would you rate the <u>attention</u> your doctor gives to what you have to say	PCAS 17b PPR communication	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
87. How would you rate the doctor's <u>explanations</u> of your health problems or treatments that you need	PCAS 17c PPR communication	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
88. How would you rate the doctor's <u>instructions</u> about symptoms to report and when to seek further care	PCAS 17d PPR communication	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
89. How would you rate the doctor's advice and help in <u>making decisions</u> about your care	PCAS 17e PPR communication	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent

90. How often do you leave your doctor's office with <u>unanswered questions</u> ?	PCAS 18 PPR-Communication	1 Always 2 Almost always 3 A lot of the time 4 Some of the time 5 Almost never 6 Never
Thinking about the <u>personal aspects</u> of the care you receive from your regular doctor/place, how would you rate the following:	PCAS PPR	
91. Amount of time your doctor spends with you, is it...(READ RESPONSES)	PCAS 19a	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
92. Doctor's <u>patience</u> with your questions or worries	PCAS 19b	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
93. Doctor's <u>friendliness and warmth</u> toward you	PCAS 19c	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
94. Doctor's <u>caring and concern</u> for you	PCAS 19d	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent

95. Doctor's <u>respect</u> for you	PCAS 19e	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
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Thinking about how much you TRUST your doctor, how strongly do you agree or disagree with the following statements:	PCAS PPR	
96. I can tell my doctor anything, even things that I might not tell anyone else, do you...(READ RESPONSES)	PCAS 23a PPR	1 Strongly Agree 2 Agree 3 Not sure (RE-READ QUES.) 4 Disagree 5 Strongly Disagree
97. My doctor sometimes pretends to know things when he/she is really not sure	PCAS 23b PPR	1 Strongly Agree 2 Agree 3 Not sure 4 Disagree 5 Strongly Disagree
98. I completely trust my doctor's judgments about my medical care	PCAS 23c PPR	1 Strongly Agree 2 Agree 3 Not sure 4 Disagree 5 Strongly Disagree
99. My doctor cares more about holding down costs than about doing what is needed for my health	PCAS 23d PPR	1 Strongly Agree 2 Agree 3 Not sure 4 Disagree 5 Strongly Disagree
100. My doctor would always tell me the truth about my health, even if there was bad news	PCAS 23e PPR	1 Strongly Agree 2 Agree 3 Not sure 4 Disagree 5 Strongly Disagree

101. My doctor cares as much as I do about my health	PCAS 23f PPR	1 Strongly Agree 2 Agree 3 Not sure 4 Disagree 5 Strongly Disagree
102. If a mistake was made in my treatment, my doctor would try to hide it from me	PCAS 23g PPR	1 Strongly Agree 2 Agree 3 Not sure 4 Disagree 5 Strongly Disagree

Thinking about how well your doctor knows you, how would you rate the following?		
READ RESPONSES		
103. Doctor's <u>knowledge</u> of your entire medical history	PCAS 25a	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
104. Doctor's knowledge of your responsibilities at work or home	PCAS 25b	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
105. Doctor's knowledge of what worries you most about your health	PCAS 25c	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent

106. Doctor's knowledge of you as a person (your values and beliefs)	PCAS 25d	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
107. If I were unconscious or in a coma, my doctor would know what I would want done for me.	PCAS 26	1 Strongly Agree 2 Agree 3 Not sure 4 Disagree 5 Strongly Disagree
108. Has your doctor ever recommended that you see a different doctor for a specific health problem?	PCAS 30	1 Yes 2 No (SKIP TO NEXT SECTION 115)
Thinking about the times your doctor has recommended you see a different doctor for a specific health problem, how would you rate the following: (READ RESPONSES FOR EACH)	PCAS 31	
109. Help your regular doctor gave you in deciding who to see for specialty care	PCAS 31a	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
110. Help your regular doctor gave you in getting an appointment for specialty care you needed.	PCAS 31b	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
111. Regular doctor's involvement in your care when you were being treated by a specialist or were hospitalized	PCAS 31c	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent

112. Regular doctor's communication with specialists or other doctors who saw you	PCAS 31d	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
113. Help you regular doctor gave you in understanding what the specialist or other doctor said about you	PCAS 31e	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent
114. Quality of specialists or other doctors your regular doctor sent you to	PCAS 31f	1 Very poor 2 Poor 3 Fair 4 Good 5 Very good 6 Excellent

For half of the interviews, have the CATI ordered so this next section of 1-10 responses comes before the primary care section, and for other half of interviews have it come after the primary care section. Create a variable that indicates whether the interview order was the former or the later.

115. All things considered, how much do you trust your doctor? (On a scale from 0 to 10 where 0 is not at all, and 10 is completely)	PCAS Item #24	(Not at all) 0 1 2 3 4 5 6 7 8 9 10 (Completely) FEED BACK RESPONSE TO BE SURE SHE UNDERSTANDS SCALE
116. All things considered, how hard is it for you to get in to see your doctor/place/nurse when you feel sick or when you need routine care or a check-up? (Answer on a scale from 0 to 10 where 0 is very hard, and 10 is very easy) (PROMPT IF NEEDED: this includes things like: getting an appointment, cost, travelling to the doctor's office, being able to get in touch with your doctor)	AO Accessibility My own item, I will compare the psychometrics of these next five items to those of the PCAS I made this up At Jeanne Mandelblatt's suggestion Reverse score	(Very Hard) 0 1 2 3 4 5 6 7 8 9 10 (Very Easy) FEED BACK RESPONSE TO BE SURE SHE UNDERSTANDS SCALE
117. All things considered, how good or bad is your <u>relationship with your doctor/place</u> ? (On a scale from 0 to 10 where 0 is very bad, and 10 very good) (PROMPT IF NEEDED: including getting an appointment, cost, travelling to the doctor's office)	AO PPR I made this up	(Very Bad) 0 1 2 3 4 5 6 7 8 9 10 (Very Good)
118. Thinking about all of your health care needs, how good is your doctor/place at taking care of <u>all</u> of your health needs ? (On a scale from 0 to 10 where 0 is very bad, and 10 is very good) (PROMPT IF NEEDED: This includes all of your sick and routine care needs, even for things which they may have to refer you to another place for)	AO Comprehensiveness	(Very Bad) 0 1 2 3 4 5 6 7 8 9 10 (Very Good)

<p>119. How good is your doctor/place at arranging for all of the services you need, even for care from specialists or special services? (On a scale from 0 to 10 where 0 is very bad, and 10 is very good)</p> <p>(PROMPT IF NEEDED: Knowing about the care you get from specialists like heart doctors or bone doctors or knowing about any social services or medical assistance that you might get)</p>	<p>AO Coordination</p>	<p>(Very Bad) 0 1 2 3 4 5 6 7 8 9 10 (Very Good)</p>
<p>120. All things considered, how hard is it for you to see the same doctor/nurse each time you go for a visit for either sick or routine care?</p> <p>(On a scale from 0 to 10 where 0 is very hard, and 10 is very easy)</p>	<p>AO Continuity</p>	<p>(Very Hard) 0 1 2 3 4 5 6 7 8 9 10 (Very Easy)</p>
<p>121. How much <u>responsibility</u> do you think your doctor/place feels for making sure that you and your community stay healthy?</p> <p>(On a scale from 0 to 10 where 0 is None and 10 is a lot)</p>	<p>AO Accountability</p>	<p>(None) 0 1 2 3 4 5 6 7 8 9 10 (A Lot)</p>

<p>People in Washington come from many different ethnic and racial groups. Everyone has different names for these groups.</p> <p>122. What do you consider yourself?</p>	<p>CODE THIS AS TWO VARIABLES, THE FIRST IS A CHARACTER VARIABLE (OPEN-ENDED QUESTION)</p> <p>THE SECOND IS NUMERIC (6 CATEGORY RESPONSE)</p>	<p>122a..</p> <hr/> <p>WRITE IN RESPONSE VERBATIM AND CHECK BELOW IF RESPONDENT OFFERS ONE OF THE FOLLOWING: (INTERVIEWER, PLEASE DO BOTH RESPONSE FORMS)</p> <p>122b.</p> <p>1 Black/African American (SKIPTO131)</p> <p>2 White/Caucasian(SKIP TO 131)</p> <p>3 Hispanic/Latina (PROCEED WITH ACCULTURATION QUESTIONS, I.E. CONTINUE WITH NEXT QUESTION)</p> <p>4 Caribbean/West Indian (SKIP TO 131)</p> <p>5 Something else (SKIP TO 131)</p> <p>6 Refused/DK (SKIP TO 131)</p>
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ACCULTURATION

BE SURE THAT ANYONE WHO ANSWERED HISPANIC/LATINA IN THE PREVIOUS QUESTION DOES GET ASKED THESE NEXT ACCULTURATION ITEMS.

ALSO BE SURE THAT IF THE PERSON IS DOING THE INTERVIEW IN SPANISH, REGARDLESS OF WHAT ETHNICITY SHE SAID SHE IS IN THE PREVIOUS QUESTION, THEN DO THE ACCULTURAITON QUESTIONS.

<p>I would now like to ask you a few questions about what language you use in different situations. (READ RESPONSES FOR EACH QUESTION)</p>	<p>Marin Acculturation Scale</p>	<p>5 Only Spanish</p> <p>4 Spanish better than English</p> <p>3 Both equally</p> <p>2 English better than Spanish, or</p> <p>1 Only English</p> <p>DK/REF</p>
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123. In general, what language(s) do you read and speak?	Marin	5 Only Spanish 4 Spanish better than English 3 Both equally 2 English better than Spanish, or 1 Only English DK/REF
124. What language(s) do you usually speak at home?	Marin	5 Only Spanish 4 Spanish better than English 3 Both equally 2 English better than Spanish, or 1 Only English DK/REF
125. In which language(s) do you usually think?	Marin	5 Only Spanish 4 Spanish better than English 3 Both equally 2 English better than Spanish, or 1 Only English DK/REF
126. What language(s) do you usually speak with your friends?	Marin	5 Only Spanish 4 Spanish better than English 3 Both equally 2 English better than Spanish, or 1 Only English DK/REF
127. Were you born in the United States ?	Supplementary acculturation variables	1 Yes (SKIP TO) 2 No 3 DK 4 Ref
128. How many years have you been in the United States?		1 Less than one year 2 ____ (TYPE IN NO. OF YEARS) 3 DK 4 Ref

129. Was your mother born in the United States ?		1 Yes 2 No 3 DK 4 Ref
130. Was your father born in the United States?		1 Yes 2 No 3 DK 4 Ref

KNOWLEDGE, ATTITUDES AND BELIEFS/Fatalism

For consistency, we will ask all participants all items, regardless of ethnicity.

(See Eliseo's and others Spanish translation too)

Fear/Attitude/Beliefs

Now I'm going to ask you about your opinions. For each question please answer yes or no. There are no right or wrong answers.

131. Do you go to the doctor for check-ups even when you are well?	Eliseo Perez-Stable Pathways to Cancer Screening, 1993 <i>En Accion Contra El Cancer</i>	1 Yes 2 No
132. Do you think that illness is a matter of chance or fate?	Eliseo Perez-Stable Pathways to Cancer Screening, 1993 <i>En Accion Contra El Cancer</i>	1 Yes 2 No
133. Do you avoid going to the doctor even when you are very sick?	Eliseo Perez-Stable Pathways to Cancer Screening, 1993 <i>En Accion Contra El Cancer</i>	1 Yes 2 No
134. Do you think that cancer is God's punishment?	Eliseo Perez-Stable Pathways to Cancer Screening, 1993 <i>En Accion Contra El Canc</i>	1 Yes 2 No

Please tell me whether you agree with each of these next statements:

135. Air causes cancer to grow faster	Lannin et al., JAMA 1998	1 Agree (Yes) 2 Don't agree (No)
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136. Surgery causes a cancer to grow faster	Lannin	1 Agree 2 Don't agree
137. Someone can give you cancer by putting a root or spell on you	Lannin	1 Agree 2 Don't agree
138. If a person prays about cancer, God will heal it without medical treatments	Lannin	1 Agree 2 Don't agree
139. People with high blood are more likely to get cancer	Lannin	1 Agree 2 Don't agree

PERSONAL CHARACTERISTICS

140. Are you now...? (READ RESPONSES.)		1 Working full time 2 Working part time 3 Unemployed 4 Retired/disabled 5 Homemaker 6 Student 7 DON'T KNOW 8 REF
141. Did you have health insurance for any of the time during the past 12 months?		1 Yes 2 No
142. Do you have health insurance now?		1 Yes 2 No
143. Which of the following types of health insurance did you have in the past 12 months? (CAN CHECK MORE THAN ONE)		1 Medicare 2 Medicaid/Charter Health 3 HMO/or Kaiser 4 Private Insurance/ or Blue Cross/Blue Shield 5 Other _____ 6 NOT COVERED BY ANY INSURANCE 7 DON'T KNOW 8 REF
144. How many days in the past month did you miss work due to being ill?		____ (days)

145. How many days in the past <u>6 months</u> did you miss work due to being ill?	See page 23, Starfield text, 1998	_____ (days)
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146. Do you own or rent your home/apartment?		1 Own 2 Rent 3 Don't pay for it ourselves
147. How much does your family pay a month in rent or mortgage?	D5 PCAT	1 Nothing (\$0/month) 2 <= \$200/month 3 \$201-500/month 4 \$500-750/month 5 \$751-1000/month 6 > \$1000/month
148. How many people live in your household?		 DK/REF
149. How much was the total combined income from all persons living in your household in 1999? I do not need to know the exact amount. Was it: (READ RESPONSES)		1 Less than \$10,000 2 \$10,000-20,000 3 \$20,000 to \$30,000 (>\$20,000 AND <=\$30,000) 4 \$30,000 to \$40,000 (>\$30,000 AND <= \$40,000) 5 Over \$40,000 6 REF /DK

We are almost done with the interview.

150. What is your zip code?	-----
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151. Have you heard of Project WISH?	Barbara Baldwin, Program Manager for Project Wish-CDC	1 Yes 2 No 3 Unsure
152. Do you know where to go in Washington, D.C. for low-cost or free breast cancer screenings?	Barbara Baldwin, Program Manager for Project Wish	1 Yes 2 No 3 Unsure
153. Do you trust free health care services?	Barbara Baldwin, Program Manager for Project Wish	1 Yes 2 No 3 No opinion

Thank you for taking the time to complete this interview. Your responses will help us to try to improve health care for women such as yourself.

Are We Getting the Message Out to All? Health Information Sources and Ethnicity

Ann S. O'Malley, MD, MPH, Jon F. Kerner, PhD, Lenora Johnson, MPH, CHES

Background: Over 80% of the excess deaths in minority and economically disadvantaged populations are from diseases with preventable or controllable contributing factors. However, mainstream health education targeting behavior change often fails to reach minority populations.

Objective: To identify the health and cancer information sources used by a multiethnic population and to determine whether information sources differ by ethnic group, age, gender, and socioeconomic status.

Methods: A multilingual, random-digit dial telephone survey of 2462 Hispanic (Colombian, Dominican, Ecuadorian, and Puerto Rican) and black (Caribbean, Haitian, and U.S.-born) persons, aged 18–80 years, from a population-based quota sample, New York City, 1992.

Results: All ethnic and age groups cited a health professional as the most common source of health information (40% overall). The next most commonly cited sources overall were: television (21%), hospitals or doctor's offices (18%), books (17%), magazines (15%), brochures/pamphlets (11%), and radio (8%). Responses on sources of cancer information followed a similar pattern. Black subgroups were all significantly more likely than Hispanic subgroups to get their health information from a doctor or other health professional ($p = 0.001$). Use of the radio as a source of health information was highest among Haitians (20.8%) and Colombians (12.5%), and lowest among U.S.-born blacks (4.2%) ($p = 0.001$), but there was no difference in the use of television. Among immigrants, as the proportion of life spent in mainland-U.S. rose, increasing percentages cited magazines ($p = 0.001$) and decreasing percentages cited radio ($p = 0.025$) as a health information source. Less educated persons and more recent immigrants were most likely to report inability to get health information ($p = 0.001$).

Conclusions: Given the variation in sources of health and cancer information, identification of those most commonly used is important to health educators' and public health practitioners' efforts to target hard-to-reach ethnic minorities.

Medical Subject Headings (MeSH): information dissemination, health behavior, ethnicity, Hispanic Americans, information distribution, communication (Am J Prev Med 1999; 17(3):000–000) © 1999 American Journal of Preventive Medicine

Introduction

Minority and economically disadvantaged communities lag behind the U.S. population overall on virtually all indicators of health status. Over 80% of excess deaths in these populations are from diseases with preventable or controllable contributing factors: cancer, heart disease and stroke, homicide and unintentional injuries, infant mortality, diabetes, and chemical (primarily alcohol) abuse.¹ However,

mainstream health education targeting behavior change often fails to reach minority populations.^{1–3}

While some data on the health information sources used by the majority population have been published,^{4–6} little information is available on the sources of health information used most often by persons of color, especially within northeastern Hispanic and black communities. Prior work comparing non-Hispanic whites and southwestern Hispanics has shown ethnic-specific preferences for certain sources of health information.^{7–9}

In addition, most studies on information sources focus on patients currently undergoing treatment for a specific disease¹⁰ rather than on the general asymptomatic population.

The purpose of this report is (1) to identify the health information sources used by the ethnic groups

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accounting for the largest percentage of blacks and Hispanics in New York City and (2) to assess how ethnicity, age, gender, language, and socioeconomic status relate to differences in health information sources used.

Methods

This study is part of a larger project assessing the general health and cancer prevention needs of Caribbean, Haitian, and U.S.-born blacks, and Puerto Rican, Dominican, Colombian, and Ecuadorian Hispanics living in all 5 boroughs of New York City. These 7 populations compose the largest subgroups of blacks and Hispanics in New York City.¹¹ The majority (75%) of the sample were immigrants. Data were collected from May to October of 1992 by experienced multilingual interviewers using computer assisted telephone interviews (CATI). The study used a quota sample to identify 50 men and 50 women from each racial/ethnic group (except for Haitians; $n = 25$ per group because they were added after grant funding) in 4 age groups: 18–44 years, 45–54 years, 55–64 years, and 65–74 years for a total goal of 2600. Details on the survey and sampling methodology have been published elsewhere.^{12–13}

Survey participants were asked in their language of preference (English, Spanish, or Creole) a previously validated,¹⁴ open-ended question: "Where do you usually get your health information?" Interviewers had a long list of potential responses which could be checked if offered by the respondent. The potential responses included:

People: (doctor/health professional [i.e., clinician], family, friend, home country, other); Cancer organizations/programs: (Cancer information services, National Cancer Institute, American Cancer Society, Telephone information-Public service or hot line, government agencies/program-unspecified, private organization/program-unspecified, other cancer organization/program-unspecified, health fairs/seminars); Non-cancer organizations/places: (church/religious place, grocery store, hospital/doctor's office, school, library, workplace, union, other local organization, other national organization, HMO/GHI/HIP-Insurance company); Electronic media: (radio, television [TV]); Printed Material: (brochure/pamphlet, book, magazine, newspaper, medical journal, encyclopedia, other); Other: (specify); and Unable to get information; None/Never looked/Don't know.

Of those who responded positively to another item on whether they had sought cancer information in the past 5 years, a further question was asked, "When you were seeking cancer information, where did you get it?"

Potential responses that the interviewer could check, if offered by the respondent, were the same as above.

We report descriptive statistics on sources of health information used by black and Hispanic ethnic subgroups stratified by personal, demographic,^{13,15–16} and socioeconomic characteristics. Stratified analyses and multivariate logistic regressions were done, using SAS (SAS Software, Cary, NC),¹⁷ to assess whether use of clinician as information source (the most commonly cited response) differed significantly by ethnicity after controlling for insurance status, proportion of life on mainland U.S., and presence of a usual source of care.

Results

The survey was completed by 2462 persons. The response rate for all calls made, including those to determine eligibility, was 62.3%. Among respondents qualifying for the survey on the basis of age and ethnicity, the refusal rate was 2.1%.

Health Information Sources Cited by the Overall Sample

For all ethnic and age groups the highest proportion of respondents (31%–63%) volunteered that a doctor or health professional was a source of health information. The next most commonly cited sources of health information for the overall sample were: television (21%), hospitals or doctor's offices (18%), books (17%), magazines (15%), brochures/pamphlets (11%), and radio (8%). Differences by ethnicity are summarized in Table 1.

T1

Cancer Information Sources for the Overall Sample

Among the 1333 respondents (54% of the total sample) who had sought cancer information in the previous 5 years, the proportions using each type of cancer information source followed a similar pattern to the responses about health information in general (clinician 22%; hospital/doctor's office 15%; radio 6.1%; television 18.7%; brochure 16.8%; book 13.1%; magazine 15.2%; newspaper 9.3%). Cancer organizations/programs (CIS, NCI, ACS) were cited by $\leq 1\%$ of respondents as sources from which cancer information was sought. Mention of the workplace (2.5%), schools (2.2%), churches/religious places (1%), libraries (1%), cancer organizations/programs ($<1\%$), unions ($<1\%$), insurance companies ($<1\%$), home country ($<1\%$), or grocery stores ($<0.1\%$) as either a general health or a cancer information source was universally low.

Table 1. Health information source reported by ethnic groups, multi-ethnic sample, New York City, 1992*

Source of Information	Total N = 2462 %	Colombian n = 329 %	Dominican N = 492 %	Ecuadorian n = 258 %	Puerto Rican n = 450 %	Caribbean n = 357 %	Haitian n = 168 %	U.S.-born Black n = 408 %	p
People									
Doctor/Health-Prof.	40.0	34.0	31.1	32.9	36.2	48.2	63.7	47.6	.001
Family	4.2	3.3	3.6	2.7	4.7	5.3	4.7	4.7	.664
Friend	3.9	2.7	3.7	1.5	4.7	4.8	4.8	4.9	.252
Non-Cancer Organizations/Places									
Hospital/Dr.'s Office	18.4	21.0	22.2	19.4	20.7	12.0	13.1	16.4	.001
School	2.2	2.7	2.6	2.7	0.7	2.0	5.4	1.2	.013
Workplace	2.5	0.3	2.2	1.6	2.7	5.0	2.4	2.7	.008
Electronic Media									
Radio	8.1	12.5	8.3	6.2	7.1	4.7	20.8	4.2	.001
Television	21.1	23.1	19.9	18.6	19.1	21.0	30.4	21.6	.065
Printed Material									
Brochure/Pamphlet	10.7	11.6	8.7	6.7	12.0	9.8	16.1	12.2	.030
Book	17.2	13.4	11.2	12.0	15.8	26.0	19.0	23.8	.001
Magazine	15.3	14.9	11.4	9.7	17.6	17.7	11.9	20.6	.001
Newspaper	9.5	6.1	9.6	6.6	10.7	9.5	8.3	13.0	.032
Medical Journal	4.8	0.9	3.0	3.1	3.8	8.7	5.4	8.8	.001
Other									
Unable to get info.	2.8	3.6	4.7	5.0	1.1	2.2	4.8	0.0	.001
None/Never looked	3.7	4.9	6.1	3.5	4.4	2.2	3.0	1.0	.002

*Only information sources reported by $\geq 2\%$ of the sample are listed in this table. (N = 2462) (Responses to open-ended question, "Where do you usually get your health information?")

Role of Social and Demographic Factors on use of Health Information Sources

Age. There was a linear increase in percentage citing the doctor/health professional as a source of health information with increasing age (18–44 years: 33.3%; 45–54 years: 38.2%; 55–64 years: 44.2%; 65 + years: 52.1% $p = 0.001$). There was a decrease in reports of use of television as an information source with increasing age ($p = 0.001$). Citing magazines or newspapers as a health information source was higher in the two younger age groups (19.3% and 11.2%, respectively) and decreased in the older age groups (10.8% and 6.3%: $p = 0.001$ and $p = 0.033$, respectively) (data not shown).

Gender. For all ethnic groups combined, females were more likely than males to get their health information from a doctor/health professional (42.5% versus 36.7%; $p = 0.003$). Males were more likely than females to get their health information from newspapers (12.9% versus 7.0%; $p = 0.001$, respectively). Similar and significant differences were found by gender for sources of cancer information (data not shown).

Educational and immigration status. Increasing education was negatively associated with citing hospitals as a source of health information. ($p = 0.002$) Television was cited as an information source among a larger percentage of more highly educated persons (high school graduates or higher) (24.3%) than less educated persons (8 years or less) (14.9%) ($p = 0.001$). Also, less

educated persons and more recent immigrants were more likely to report being unable to get health information ($p = 0.001$). As proportion of life spent in the mainland-U.S. increased, higher percentages cited magazines as a source of health information ($p = 0.001$) and conversely, lower proportions cited radio as a source of health information ($p = 0.025$) (data not shown).

Insurance. Since insurance is the most powerful predictor of access to the health care system, it was not surprising that the highest proportion of persons saying that they usually get their health information from a doctor/health professional was privately insured (55.4% private, 28.0% public, and 16.5% uninsured $p = 0.001$). Among the insured, similar proportions cited the doctor/health professional as a usual source of health information (45.2% for private and 42.8% for public); whereas only 27.9% of uninsured persons cited the doctor/health professional as a usual information source ($p = 0.001$). Use of print materials as information sources (brochures/pamphlets, books, magazines, and newspaper) was highest among the privately insured (data not shown).

Ethnicity. When the Hispanic groups' use of television as a health information source was stratified by a language-based acculturation measure, ethnic differences did emerge. Among less acculturated Hispanics (those who used Spanish more than English with family, friends, co-workers, and in media-consump-

tion), 23% of Colombians, 18% of Dominicans, 19% of Ecuadorians versus only 11% of Puerto Ricans reported using TV as a source of health information ($p = 0.04$). Among the more acculturated Hispanic groups, there were no significant differences in TV use. For all other forms of media there were no significant ethnic differences within each mode's use as health information source when stratified by acculturation (data not shown).

Multivariate logistic regression models, in which use of a clinician as information source was the dependent variable, were done to assess whether ethnic subgroup was a significant predictor after controlling for insurance status, proportion of life in the U.S., and presence of a usual source of care.^{12-13,18} Compared to U.S.-born blacks (reference group), Dominicans and Puerto Ricans were significantly less likely (OR = 0.731, 95% CL: 0.55-0.96; OR = 0.742, 95% CL: 0.57-0.96, respectively) and Caribbeans and Haitians were significantly more likely (OR = 1.44, 95% CL: 1.1-1.9; OR = 3.0, 95% CL: 2.1-4.4, respectively) to use a clinician as information source. Thus, ethnic subgroup, insurance, and presence of a usual source of care remained significant predictors of use of a clinician as a health information source (data not shown).

Conclusions

This study found wide variation by ethnicity, age, gender, socioeconomic status, insurance, and the proportion of life spent in the U.S. in the sources of health and cancer information reported.

In research on the perceived credibility⁷ and frequency^{10,19-21} of information sources among Mexican-American Hispanics and non-Hispanics whites, physicians were reported as most credible and most frequently used.^{7,10,19-21} Given good evidence that clinicians can change some patient behaviors through simple counseling interventions in the primary care setting,²¹⁻²⁴ it is reassuring to find that this was the usual source of health information cited by the largest percentage of respondents. This also highlights the importance of patient-provider communication in information dissemination to higher risk groups.

In terms of comparisons between the non-Hispanic white population and persons of color, National Health Interview Survey data indicate that African Americans are more likely than whites to receive some types of health information (e.g., HIV information) by reading brochures or listening to the radio.²⁵ In other studies of HIV information, urban African Americans and Hispanics were more likely to rely on mass media sources (e.g., television) whereas whites were more likely to receive information through targeted small media (e.g., brochures),²⁶ newspapers, or magazines.²⁷ Use of English print media is likely related to language preference and acculturation level. In this study, respon-

dents were not asked to specify whether the forms of print media used were in English or Spanish, so associations between language skills and media language consumption could not be ascertained.

Health communication efforts through mass media have been shown to be most effective when combined with community-based programs.²⁸ In this study, less educated (≤ 8 years of school) and less acculturated persons had difficulty obtaining health information. This difficulty may have been due to low literacy levels, poorer access to media and health professionals, preoccupation among recent immigrants with socioeconomic survival, or lack of knowledge of where to go for health information. Traditional media sources may be less promising avenues for reaching higher-risk persons. More grass-roots community-based efforts (e.g., use of lay health workers or targeting barrios) may be necessary to effectively target these groups.

There is too little literature on health information sources in minority groups to verify whether changes in information campaigns have occurred since these data were collected. At the very least, these data serve as a baseline of health information sources used in this multi-ethnic community, and can help inform strategies to target these populations. One source of information used with increasing frequency since 1992 is the Internet; however, its accessibility to this population is unclear. Other methodological limitations in these data have been described elsewhere.¹²⁻¹³

This study described health information sources used by hard-to-reach members of these ethnic groups. Further study of the effectiveness of these information sources in promoting behavior change in these communities is needed. Given that these hard-to-reach populations have rates of preventable deaths in excess of the majority population, renewed efforts to provide culturally appropriate and educationally tailored messages and materials to these populations must be given serious consideration.

This research project was supported by the following grants: DAMD 17-97-1-7131 (P.I. Ann S. O'Malley) and NCI R01CA53083 (P.I. Jon Kerner).

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MARCH 18-21, 1999 • WASHINGTON, DC

PREVENTION 99

SCIENTIFIC, POLITICAL AND SOCIAL PRIORITIES FOR THE 21ST CENTURY

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TO: Ann O'Malley

FROM: Jodi M. Lehner, Meeting Director

RE: Abstract #: 138

Title: Health Information Sources Used By A Multi-Ethnic Population

We are very pleased to offer you the opportunity to exhibit and present a poster describing your work at **PREVENTION 99: Scientific, Political & Social Priorities for the 21st Century** at the Crystal Gateway Marriott in Arlington, Virginia. Congratulations!

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All posters will be displayed Friday, March 19 at 3:00 pm- Saturday, March 20 at 10:45 am. Special non-competing program time has been set aside for Friday, March 19, from 6:00-8:00p.m. for poster authors to present their work to meeting attendees during a special "Poster Reception." All poster boards will be set up in the Arlington Ballroom in the Crystal Gateway Marriott Hotel.

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An updated **PREVENTION 99** registration brochure will be mailed to you in mid January. For your reference, I have enclosed another copy of the earlier registration brochure that was mailed in November. **All attendees, including presenters, must register for the meeting.**

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HEALTH INFORMATION SOURCES USED BY A MULTI-ETHNIC POPULATION

Ann S. O'Malley MD, MPH; Jon Kerner PhD; Lenora Johnson MPH, CHES. Georgetown Univ. Med. Ctr.

OBJECTIVES: To identify the health and cancer information sources used by a multiethnic population; to determine whether information sources differ by ethnic subgroup, age, gender and socioeconomic status.

METHOD: A bilingual, targeted random-digit dial telephone survey of 2462 Hispanic (Colombian, Dominican, Ecuadorian and Puerto Rican) and black (Caribbean, Haitian and US-born) persons, aged 18-80 years, from a population-based quota sample in New York City, 1992. Respondents were asked about sources of general health information and of cancer information via validated questions.

RESULTS: The response rate for all calls made was 62.3%. Among respondents qualifying for the survey based on age and ethnicity, the refusal rate for completed interviews was 2.1%. For all ethnic and age groups the highest proportion of respondents (31-63%) volunteered that a doctor or health professional was a source of health information. The next most commonly cited sources of health information for the overall sample were: television (21%), hospitals or doctor's offices (18%), books (17%), magazines (15%), brochures/pamphlets (11%), and radio (8%). Responses on sources of cancer information followed a similar pattern. Black subgroups were all significantly more likely than Hispanic subgroups to get their health information from a doctor or health professional (p=.001). Use of the radio as a source of health information was highest among Haitians (20.8%) Colombians (12.5%) and Dominicans (8.3%) and lowest among US-born blacks (4.2%) (p=.001), but there was no difference in the use of television. TV was an information source among a larger percentage of higher educated (high school graduates: 24.3%) than less educated persons (8 years or less: 14.9%) (p=.001). There was a linear increase in the percentage citing the doctor/health professional, and a decrease in percentage citing TV, as information source with increasing age (p=.001). Less educated persons and more recent immigrants were more likely to report inability to get health information (p=.001). As proportion of life in mainland-U.S. increased, higher percentages cited magazines and lower percentages cited radio (p=.025) as a source of health information (p=.001).

CONCLUSION: Given the variation in sources of health and cancer information, identifying the most commonly used sources is important to health educators' and public health practitioners' efforts to target hard-to-reach populations such as racial and ethnic minorities.

ABSTRACT DEADLINE:
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Low-Income Women's Priorities for Primary Care : A Qualitative Study

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1 (very short) appendix (table created in response to all reviewers' comments)

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Low-Income Women's Priorities for Primary Care

Abstract:

Background: Due to their challenging social and economic environments, low-income women may find particular features of primary care uniquely important. This qualitative study explores the particular features of primary care which are priorities to women from low-income settings; and, whether those priorities fit into an established primary care framework.

Methods: Qualitative analysis of four focus groups of female patients, ages 40-65, from four community health clinics in Washington, D.C.. Prompted by semi-structured open-ended questions, the focus groups discussed their experiences with ambulatory care, and attributes of primary care that they found important. Focus groups were audio-taped, transcribed verbatim, and coded independently by three readers.

Results: Consensus codes were organized into five content areas of primary care service delivery and the patient-provider relationship. The percentages of separate comments falling into each area were as follows: accessibility (37.4%), the patient-provider relationship (37.4%), comprehensive scope of services (11.5%), coordination between providers (6.8%), continuity with a single clinician (3.7%), and accountability (3.2%). Commonly reported specific priorities included: having a sense of concern and respect from the clinicians and staff toward the patient; having a physician who was willing to talk and spend time with them (attributes of the patient-provider relationship); week-end or evening hours, waiting times (attributes of organizational accessibility); location in the inner-city and on public transport routes (an attribute of geographic accessibility); availability of coordinated social and clinical services on-site; and, availability of mental health services on-site (attributes of comprehensiveness and of coordination).

Conclusions: All attributes of care that were priorities for low-income women fit into one of six content areas. Specific features within the content areas of accessibility, patient-provider relationship and comprehensiveness were particularly important for these women. A population-based survey which captures the relative value low-income women place on specific attributes within each of these six content areas can inform future efforts to improve health care delivery to this vulnerable population.

Key words: Primary care, low-income, priorities, preferences, satisfaction, women

Background:

Early research on community interventions in primary care for vulnerable populations has shown that it improves routine illnesses (such as strep throat and hypertension), health status, decreases preventable hospitalizations, and reduces the use of emergency rooms.¹⁻⁸ The literature examining specific attributes of the structure and process of primary care for lower income populations, who suffer from disproportionately poor health,⁹ is relatively modest.¹⁰ Most research has been undertaken in predominantly insured middle-class private settings, and in children.¹¹⁻¹⁶ Furthermore, conceptualization of “optimal primary care” from the perspective of poor persons has not been well studied. There may be particular features of primary care which are uniquely important to low-income women given the challenging social and economic environment in which they operate.

Ideally, *primary care* provides entry into the system for all new health needs, is person-focused (not disease-oriented) care over time, includes care for all but very uncommon or unusual conditions, and coordinates services delivered by multiple providers.¹⁷ Within the well accepted conceptual frameworks of primary care, the essential features include: a comprehensive range of services, coordination across providers, continuity with a single provider, an accessible source of care, and accountability.¹⁷⁻¹⁸

The purpose of this qualitative study was: to determine which particular attributes of primary care are priorities for low-income women, and to investigate whether an accepted framework for the conceptualization of primary care (i.e. *comprehensive range of services, coordination across providers, continuity with a single provider, an accessible source of care, and accountability*)¹⁷⁻¹⁸ corresponds to the priorities of low-income women aged forty and over. We hypothesized that themes raised by low-income women would fit into an established

framework of primary care,¹⁷⁻¹⁸ but that particular attributes of the features of primary care would be especially important to this vulnerable population.

Methods:

Study Design:

Focus group participants were recruited through posters and flyers circulated at four community-clinics in Washington, D.C. The four clinics were selected because of their location in medically under-served communities within three of the poorest wards of Washington D.C., and because they were examples of the range of community clinics in terms of structure and funding sources. Two serve a low-income predominantly African-American population, one serves a mainly Spanish-speaking Hispanic population, and the remaining clinic (a designated CHC) serves low-income Hispanic and African-American populations. All clinics had the goal of providing primary care to persons residing in D.C. who were uninsured, underinsured or who may have had Medicaid.

In-depth interviews, focus groups¹⁹ and content analysis of the transcripts²⁰ were used to identify attributes of primary care that are important to low-income women. Through an iterative process of listening to audio-tapes and reading transcripts, an exhaustive taxonomy was created which identified groups of issues that low-income women identified as important in the receipt of primary care.

Focus-Group Participants:

Participants had to: be English or Spanish speaking, be females age ≥ 40 years, have used the clinic for their care presently, or in the past, and be able to give informed consent. Since this

qualitative study is the first component of a larger study to assess the relationship between priorities for primary care and receipt of preventive (cancer screening) services for low-income women, the sampling frame was restricted to women age 40 and over.

Recruitment:

Posters advertising the focus groups (with a phone number to call) were placed throughout the clinics. Clinic staff also mentioned the focus groups to patients. Volunteers were screened prior to participation by telephone to assure that eligibility requirements were met. Participants were reimbursed with \$20 and breakfast. Upon completion of the fourth focus group, similar themes continued to be raised, indicating saturation of themes.

Conduct of Focus Group Sessions:

A separate focus group was held for each of the four clinics. Clinic staff was not present at the focus groups. All focus groups were conducted in safe, neutral and convenient community settings. The sessions lasted approximately two hours. A total of 24 women participated in the four focus groups. The two focus groups conducted for the clinics serving predominantly English speaking low-income African American populations were facilitated by a trained independent African-American moderator with extensive experience conducting focus groups in this population. The two focus groups for the two clinics which serve mainly Spanish speaking patients were conducted in Spanish (and later transcribed and translated) by a trained and experienced Latin American age-appropriate female moderator with experience working in health care in the Latin community in D.C. All focus groups were audio-taped and transcribed verbatim.

A series of open-ended questions was asked of focus group participants to elicit their feelings about and experiences with primary care at their respective clinics. (See appendix)

Development of Taxonomy:

Two study team members (an internist and a physician-researcher) independently reviewed each transcript in its entirety, identifying distinct topics (themes) and making comments indicating each of these units of text. Repeated or reworded statements of the same idea by the same participant were listed together as one comment.

Each '*unit of text*' (a statement which conveyed a singular idea) from the transcripts was listed by a physician-primary care researcher in the order they arose in the transcripts, as both a direct quote and as a summary theme based on the comments made by the first two study team members. Initially, in order to avoid imposing any particular primary care framework onto women's comments, two investigators independently did **inductive coding**,²¹⁻²² in which every distinct unit of text was reviewed within its context from the transcript, categories (labels) were generated, and a list of these labels compiled. Upon reviewing this exhaustive list, we found that the list of inductive labels (codes) fit fairly well into established conceptual frameworks for primary care. Thus, all units of text from the transcripts were then re-classified independently in duplicate (by a clinical internist and by a physician primary care researcher), using agreed upon coding rules from the primary care conceptual framework, (with the addition of the category of the patient-provider relationship which arose as a common theme from the transcripts).

Inter-rater reliability for the overall coding of distinct units of text into one of six major primary care content areas was substantial (Kappa=0.84 overall). Content analysis was performed on the comments for all four focus groups including a count of the number of times a theme was mentioned by different respondents and the primary care content area into which that theme fit.

Results:

Twenty-four women participated in the discussions: 8 Latinas, 15 African-American and 1 Anglo immigrant. The mean age of participants was 46.6 years (median 44.5, one-third over age 50.) Eight of the participants had an 11th grade education or less, 5 were high school graduates, and 11 had some college. Four were currently married. The majority worked: 8 full-time, 8 part-time and the rest were unpaid, retired or unemployed. Sixteen cared for children or dependents part- or full-time. Household annual incomes were: (< \$10,000. (14 women); \$10,000-20,000. (6); >\$20,000. (2); and two declined to respond). Income distribution reflects success in recruiting the population sought. Twenty-two women were currently uninsured, but most of the African-American participants had Medicaid or private insurance in the past.

The most important conceptual modification arising from the women's comments was the addition of the provider-patient relationship as an important and unique feature encompassing many of the women's priorities. The percentages of focus group participant comments falling into each of the major primary care codes were as follows: an accessible source of care (37.4%), the patient-provider relationship (37.4%), a comprehensive range of services (11.5%), coordination across providers (6.8%), continuity with a single provider (3.7%) and accountability (3.2%). Table 1 gives the frequency distribution of low-income women's priorities for primary care.

Within the content area of the *patient-provider relationship*, themes mentioned most often were: communication between physician and patient, having staff who "listen," getting "personal attention," and most importantly, a staff which was "concerned" and "respectful." For Latinas, clinicians' knowledge of the Latin community, and of the fear/trust issues experienced

by recent immigrants toward the medical system and toward other members of the community were mentioned often.

Specific attributes mentioned frequently within the category of *accessibility* were a clinic which: 1) had evening and weekend hours, 2) was open to all regardless of insurance status, 3) was located in inner city or on public transport, and 4) was attentive to waiting times. Among Latinas, having a doctor fluent in Spanish and from a similar cultural background was an additional priority.

Within the category of *comprehensiveness*, the most frequently mentioned themes were the: availability of multiple services at one site, presence of an intake procedure that recognized one's needs, coordination of medical and social services on-site, and the availability of counseling and treatment for emotional/mental health concerns. Table 2 presents sample quotes from the focus group transcripts, organized within the six content areas along with a definition of each.

Discussion

This qualitative study identified specific priorities for primary care in a sample of low-income women from Washington, D.C.. Participants' comments could be categorized into one of 5 primary care delivery content areas: accessibility, comprehensive scope of services, coordination between providers, continuity with a single clinician, accountability, and the patient-provider relationship. Eighty-six percent of participants' comments fit into one of three content areas: patient-provider relationship, accessibility, and comprehensiveness.

While patient-provider interactions occur in referral/specialty care, the "breadth and depth"¹⁷ of those interactions in primary care make its patient-provider relationship unique.

Heavy emphasis on interactions with their primary care physicians (one-third of all comments) supports statements made in the past that vulnerable patients place a special emphasis on the provider-patient relationship.²³⁻²⁴ Having a sense that the provider had concern and respect for the patient was the most frequently mentioned priority in the focus groups. This may reflect perceptions of poorer care from providers, different expectations toward the provider held by less educated or lower income persons, and/or possible perceptions of discrimination. It is known that underinsured persons, lacking access to alternate providers, have a heightened reliance on the clinician's competence, skills and good will.²³ When working with low-income minority or immigrant patients, providers might want to be especially sensitive to their voice, tone and posture, in order to communicate a sense of respect and concern for patients who may already feel vulnerable. It appears that the category of *patient-provider relationship* is vital to the conceptual framework of primary care for these low-income women; and, it may be a link in the chain without which the other features (continuity, comprehensiveness, coordination, accessibility, accountability) cannot function optimally.

Accessibility was also a clear priority for these women. Twenty-two of the 24 women in this study were currently uninsured. This may explain why a large percentage of their comments (37.4%) fell into this category. Even though these uninsured women were now receiving medical care in community clinics, issues of access (particularly of organizational access) were still foremost in their minds. This may be due to previous obstacles encountered to obtaining care, or to deficiencies or strengths which they saw in their current ambulatory care systems. Juxtaposed against the reality of increasing under-insurance for even basic access to services, this underscores a serious and worsening problem of unmet health care delivery needs. This emphasis

on accessibility demonstrates the need to improve both the financing and organization of the primary care safety net.

The themes most frequently raised with respect to *comprehensiveness* may highlight how the needs of economically vulnerable persons differ from those who are financially secure. For example, prior research shows that poor women have a higher prevalence of mood disorders than the general population.²⁶ Yet, lower income people often do not have the choice available to higher income people, of going directly to specialty mental health services. Moreover, a large proportion of patients suffering from psychiatric symptoms would actually prefer to be treated in the primary care setting.²⁷⁻²⁹ Having treatment for depression available at the primary care site was frequently stated as being important to the participants. This argues for the provision of basic mental health care for the more common and treatable mood and anxiety disorders in the primary care setting. Thus, stronger ties between primary care and certain specialty services may be needed to ensure such comprehensiveness.

Comparison of this study's participant priorities to those of the general population from the literature, yields similarities and differences. A study of attitudes toward ambulatory care found differences in where patients placed their importance by sociodemographic characteristics.³⁰ Younger patients valued coordination of care and technical proficiency most, while older patients ranked continuity of provider and comprehensiveness highest.³¹ Older patients placed more emphasis on cost issues,^{23,31} and on attributes of accountability.^{25, 32-33} Differences have also been shown by health status: patients with a chronic illness preferred continuity over other features.³¹ Qualitative studies on attributes of ambulatory care most important to the general population have found that accessibility; coordination; information,

communication, education; respect for patients' values, preferences and expressed needs; and emotional support are the greatest concerns.³⁴ Population differences in priorities demonstrate that primary care systems must be tailored to the specific needs and priorities of the populations served.

Comparison of this study's findings to those of the general population raises the issue of what these low-income women were not saying. For example, issues of accountability were infrequently mentioned. This may reflect the participants' greater concerns of simply having accessible care. Secondly, continuity of provider, while accounting for only 3.7% of comments, was still tied to other specific attributes seen as important by the women. For example, attributes of the patient-provider relationship, such as communication, are directly tied to the presence of an ongoing relationship with a clinician over time. Furthermore, given the dependence of economically vulnerable persons on their primary care provider for access to services, and the importance this provider takes on in coordinating their care, continuity seems especially important.²³

Several limitations should be considered in interpreting these findings. First, the research questions in this exploratory study were investigated through focus groups and qualitative analysis. Such methods, if mindful of established standards²⁰ can yield well-grounded, rich and detailed data. However, we cannot ascertain their generalizability. Further work to rank women's priorities for primary care and to tie them to utilization and health outcomes, will be pursued in the future through a population-based study. Second, qualitative data are subject to researcher bias. Use of three independent raters in this study, and careful attention to coding using established methods²⁰ should have minimized this.

In summary, established frameworks for primary care¹⁷⁻¹⁸ with the addition of the category of patient-provider relationship, have qualitative (content) validity in this sample of low-income women; therefore, these content areas provide a useful language to discuss their health care delivery needs. The patient-provider relationship, accessibility and comprehensiveness appear to be the categories into which most of these women's specific priorities fall. Such qualitative data will better inform the design of a future population-based survey of low-income women's health care delivery needs. Health systems that fail to address low-income women's specific needs, may not adequately meet their clients' expectations for health care. In planning the efficient distribution of health care services, consideration of low-income women's priorities, will help to improve the quality of primary care for vulnerable populations by making it patient-centered and responsive to their specific needs.

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Table 1. Low-Income Women's Priorities for Primary Care Identified in Focus Groups.

* Percentage of total comments for which each content area accounted

** (Number of times each specific theme was mentioned by different individuals)

I. Accessibility		37.4% *
<ul style="list-style-type: none"> ▪ Available to those without insurance/ Low costs of services (12)** ▪ Attentiveness to waiting times to get an appointment and to be seen once at clinic (12) ▪ Weekend-evening hours/ Convenient appointment times (10) ▪ Doctor and staff fluent in Spanish/ Test results mailed in Spanish (Hispanic participants) (9) ▪ Location in inner city or on public transport (9) ▪ Welcoming staff / Intimacy of clinic atmosphere (5) ▪ Cleanliness and space of the facility (5) ▪ Appropriate triage of acute symptoms by front desk/ Available 24-hour nurse on call (5) ▪ Ability to get in touch and have adequate time with one's physician (4) 		
II. Patient-Provider Relationship		37.4%
<ul style="list-style-type: none"> ▪ Concerned, respectful staff (29) ▪ Doctor willing to talk and listen to you (10) ▪ Clinician from the same culture/ Knowledgeable about the immigrant community (Hispanic participants) (7) ▪ Personal Attention / Staff reaches out to you (5) ▪ Over emphasis on billing rather than on patient care (5) ▪ Competent staff (4) ▪ Sense that provider cares because s/he persists in follow-up of test results, missed appointments, missed tests (4) ▪ Personality of staff / Staff's morale (2) ▪ Absence of fear of the clinician/Clinician has patience (2) (Hispanic participants) ▪ Absence of racism (1) 		
III. Comprehensiveness		11.5%
<ul style="list-style-type: none"> ▪ Multiple services available on-site: Mental health, Counseling, Dental, Preventive (8) ▪ Up-to-date facility and equipment (6) ▪ Intake procedures that recognize needs (4) ▪ Information sources at the clinic, ex. Bulletin boards, classes, programs (2) ▪ Variety of medications offered at site (1) ▪ More access to research protocols (1) 		
IV. Coordination		6.8%
<ul style="list-style-type: none"> ▪ Integration of social services- (SSI, HUD, food stamps etc.) (5) ▪ Ease of getting well coordinated referrals to outside services and to a wide range of hospitals (5) ▪ Efficiency of services, flow between lab and clinicians (3) 		
V. Continuity		3.7%
<ul style="list-style-type: none"> ▪ Providers that you know from the past (6) ▪ Personal chemistry with staff can be maintained over time (1) 		
VI. Accountability		3.2%
<ul style="list-style-type: none"> ▪ Quality of care (3) ▪ Reputation in the community (2) ▪ Happy with care (satisfaction) (1) 		

Table 2. Sample Comments from the Focus Groups Organized by Primary Care Content Areas.

<u>Category</u>	<u>Definition</u>	<u>Sample Comments</u>
I. Comprehensiveness	Primary care facilities must be able to arrange for all type of health care services, even those not efficiently provided within the facility. A comprehensive approach must at least involve 4 steps of the medical process: problem (needs) recognition, diagnosis, management and reassessment. ¹⁷	"It's really surprising, all the things that are going on in that one clinic. In some ways it's better than a private doctor."
		"They even have someone to talk to you about depression."
		"The screening process is important. When you first go there, they learn what is going on with you, what your needs might be. During the screening process, she found out that I needed counseling for some family issues. And, I didn't even ask."
		"I went in to get more blood pressure medicine, and instead of just giving me the medicine, the doctor said that I was supposed to have this done, breast exam, pap smear, shots....The doctor took the time to give me all this stuff."
II. Coordination	Provider is capable of integrating all the care that patients receive. ¹⁷⁻¹⁸	"They (clinic staff) kept calling me to reach me about my mammogram. It really made me feel good to know that there is someone there who really cares."
		"I think the clinic should have a doctor and social worker to go through social security, because if you have a disability, you have to go through a whole lot of problems with your disability."
III. Continuity	Care over time by a single individual or team of health care professionals, (Starfield equivalent: longitudinality) and the effective and timely communication of health information. ¹⁷⁻¹⁸	"I had a long treatment and then my Medicaid was cut. The relationship between the doctor and the patient is very important. I wanted to see the same doctor."
		"I want a doctor who gets to know me."
IV. Accessibility	The ease with which a patient can initiate an interaction for any health problem with a clinician (e.g., by phone or at a treatment location) and includes efforts to eliminate barriers such as those posed by geography, administrative hurdles, financing, culture and language. ¹⁷⁻¹⁸	"The clinic needs to be right here, in my neighborhood, or near a bus or subway."
		"You shouldn't have to wait all day to be seen."
		"I had chosen a private doctor myself; but, I could never talk to her. I could never get in contact with her—so, that's when I ended up coming back [to the clinic]."
		"Communication gets lost with translation. It is not the same if you explain directly to the doctor what you feel, than to tell somebody else who will translate to the doctor in their own way."
V. Patient-Provider Relationship	Includes: Communication, Compassion, Competence, No Conflict of Interest (advocacy for the patient is primary), Context of Family and Community (provider sensitive to this) ^{18, 35}	"It's the whole staff that makes you feel like a human being, and that you are important."
		"I think they give really good care, because the first time I came here, they explained to me what was going on."
		"That doctor I was going to first, if a ran out of medicine, she'd write the prescription over the phone. But the doctor I have now, she says, 'Oh no, Mrs. S__, you have to come in here and let me check you out first, then I'll give you your prescription if I think you need it.' She's real good. She makes me come in to see if I need a different dose. And, I like that."
VI. Accountability	Clinicians and systems are responsible to their patients and communities for addressing a large majority of personal health needs and for: (1) quality of care, (2) patient satisfaction (3) efficient use of resources and (4) ethical behavior. ¹⁸	"You want a high level of health care at a totally professional level."
		"If it has a good reputation, you go there, and if you still receive that type of treatment that everybody else says that they are getting there, then that makes you want to go back. Like at [Medicaid managed plan X], I've been there more times in the last couple of months, than I'd been with my other [private] doctor."

Appendix

Focus Group Questions:

1. When you think about the place where you go for health care, what kinds of things are most important to you?
2. What do you think about the care that you receive at (XYZ) clinic?
3. What are the good things about your care there?
4. What are the bad things about your care?
5. Is there anything about your care that could be improved ?
6. What would keep you from coming to (XYZ) clinic if you needed care or had any type of questions about your health?
7. What would be the characteristics of the ideal clinic, that would make you want to go there for your care?
8. Where would this clinic be located?

A short demographic questionnaire was circulated and read aloud with the women at the end of each focus group.

Acculturation and Breast Cancer Screening Among Hispanic Women in New York City

ABSTRACT

Objectives. This study investigated whether acculturation was associated with the receipt of clinical breast examinations and mammograms among Colombian, Ecuadorian, Dominican, and Puerto Rican women aged 18 to 74 years in New York City in 1992.

Methods. A bilingual, targeted, random-digit-dialed telephone survey was conducted among 908 Hispanic women from a population-based quota sample. Outcome measures included ever and recent use of clinical breast examinations and mammograms. Multivariate logistic regression models were used to assess the effect of acculturation on screening use.

Results. When demographic, socioeconomic, and health system characteristics and cancer attitudes and beliefs were controlled for, women who were more acculturated had significantly higher odds of ever and recently receiving a clinical breast examination ($P \leq .01$) and of ever ($P \leq .01$) and recently ($P \leq .05$) receiving a mammogram than did less acculturated women. For all screening measures, there was a linear increase in the adjusted probability of being screened as a function of acculturation.

Conclusions. Neighborhood and health system interventions to increase screening among Hispanic women should target the less acculturated. (*Am J Public Health.* 1999;89:219-227)

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Despite the fact that Hispanic women have lower incidence rates for breast cancer than White non-Hispanic women, Hispanic women who do develop breast cancer are more likely to die of the disease.¹⁻⁶ This mortality differential is, in part, related to Hispanics' being diagnosed at a later stage of breast cancer than White non-Hispanics, even after adjustment for socioeconomic status and duration of symptoms.^{2,7,8} This stage differential is likely related to differential screening use.^{6,9-11}

Socioeconomic status and having health insurance, having a usual source of care, and having a physician's recommendation for screening all predict screening use in both non-Hispanic and Hispanic women.¹¹⁻¹⁶ Another factor that may influence breast cancer screening use by Hispanics is acculturation.¹⁷⁻²² Acculturation has been defined as "the psychosocial adaptation of persons from their culture of origin to a new or host cultural environment."^{23(p90)} For immigrants from non-English-speaking countries, acculturation includes the choice of language for use in daily life.²⁴

Previous studies of the role of acculturation in breast cancer screening have largely focused on Hispanics as a whole, and these studies have had mixed findings.¹⁷⁻²¹ When ethnic subgroups have been identified, the focus has been on Mexican Americans, and to a lesser extent on Cubans and Puerto Ricans, in California and the Southwest.¹⁷⁻²¹ The ethnic composition of New York City's Hispanic population (1 737 927 persons) differs from that of the southwestern United States; in 1990, the 4 largest Hispanic subgroups in New York City were Puerto Rican (49.5%), Dominican (19.1%), Colombian (5%), and Ecuadorian (4.5%).²⁵ The issue of acculturation and breast cancer screening among these northeastern Hispanics has received little attention. The purpose of this study was to assess the extent to which

acculturation plays a role in the use of recommended clinical breast examinations and mammograms in these 4 groups.

Methods

Survey Design and Sampling

This study was part of a larger study of cancer prevention and control needs of Caribbean-, Haitian-, and US-born Blacks and Puerto Rican, Dominican, Colombian, and Ecuadorian Hispanics living in New York City in 1992.^{15,26} The 4 Hispanic subgroups in the larger study comprised 908 women, who are the focus of this study. These 4 subgroups constituted the largest subgroups of Hispanics in New York City according to census data available at the time of the survey.^{25,27}

In the present study we used a quota sample to identify 50 women from each of 4 age groups—18 to 44 years, 45 to 54 years, 55 to 64 years, and 65 to 74 years—in each of 4 Hispanic groups, for an initial goal of 800 women. Because of an administrative oversight unrelated to sample characteristics, Dominicans aged 18 to 44 years were inadvertently oversampled. Since the quota sample was chosen to provide groups

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with similar age distributions, it allowed the acquisition of adequate numbers of respondents of all ages for each ethnic group.²⁸

A comparison of this quota sample's characteristics with those of an area probability sample, the sample of the Census Bureau's Current Population Survey during the same time period, suggests that our sample is comparable to the weighted probability sample of New York City Hispanics on several demographic parameters unrelated to the quota sampling framework.²⁹

The study sample was selected from the telephone exchanges for all 5 boroughs of New York City. Both list and random-digit-dialed sampling techniques were used to ensure coverage of households with unlisted numbers and members of the 4 ethnic groups. Targeting procedures employing census data, zip codes, and telephone exchanges were used to locate low-count ethnic groups clustering in specific neighborhoods.

Data Collection

Community leaders reflecting the cultural backgrounds of the study population were extensively involved in the study design and survey promotion. The instrument was developed with existing national survey items^{20,30-36} and modified for use in the target populations. New items were also designed and validated. The survey content areas were then reviewed by focus groups and community advisors from the ethnic communities. Spanish versions of the survey were pilot tested and were validated through standard translation and back-translation. Respondents could choose to be interviewed in Spanish or English. All data were collected via computer-assisted telephone interview from May to October 1992.

Dependent Variables

Use of clinical breast examinations and use of mammograms were the outcome measures. Two dichotomous variables were used for each screening procedure. The first variable was whether the respondent had ever had the procedure. She was asked, "Have you ever had a mammogram?" and "Have you ever had a breast physical exam by a doctor, nurse, or medical assistant?" The respondent was given definitions of the procedures before being asked about use.

The second dichotomous variable was whether the woman had recently been screened. She was asked, "When did you have your last mammogram?" and "About how long has it been since you had a breast physical exam by a doctor, nurse, or medical assistant [≤ 1 , 1-2, 2-3, or >3 years]?"

TABLE 1—Characteristics of the Sample of Hispanic Women (n = 908) in a Study of Cancer Prevention and Control Needs: New York City, 1992

	Ethnicity, %				P
	Colombian (n = 202)	Dominican (n = 308)	Ecuadorian (n = 151)	Puerto Rican (n = 247)	
Age, y					
18-44	31.2	50.7	34.4	37.3	
45-54	24.7	16.6	32.5	20.7	
55-64	25.3	16.6	22.5	21.1	
≥ 65	18.8	16.2	10.6	21.1	.001
Education					
<12 y	40.6	51.6	45.7	46.1	
12-15 y	45.5	37.6	46.4	40.9	
College graduate	13.9	10.7	7.9	13.0	.161
Marital status					
Married	45.5	41.2	53.0	36.4	
Single	54.5	58.7	45.7	62.7	.008
Household income, \$					
<20 000	38.6	49.0	37.1	35.2	
$\geq 20 000$	26.2	22.4	25.2	38.1	
Missing ^a	35.1	28.6	37.6	26.7	.001
Health status					
Excellent-very good	32.7	33.1	37.1	32.8	
Good	33.2	23.4	28.5	32.0	
Fair-poor	30.2	39.6	33.8	31.6	.321
Age at immigration, y					
≤ 16	9.4	18.2	7.3	53.9	
> 16	90.6	81.8	92.7	46.1	.001
Interview language					
English	9.4	14.0	8.6	42.1	
Spanish	90.6	86.0	91.4	57.9	.001
Acculturation					
Lower	75.7	76.9	77.5	37.8	
Higher	24.3	23.1	22.5	62.2	.001
Employment status					
Unpaid	43.1	52.6	36.4	39.3	
Retired	12.9	15.3	15.9	17.8	
Part-time	14.4	5.2	7.3	6.9	
Full-time	29.2	26.3	39.1	35.2	.001
Insurance status					
Uninsured	35.6	26.0	36.4	8.1	
Medicaid/Medicare only	22.8	43.2	27.8	40.5	
Private	39.1	28.6	33.1	49.0	.001
Has a usual source of care	80.7	80.5	82.8	90.7	.006

^aIncome was missing for women who refused to answer the question or answered "Don't know."

"Recent" was defined according to 1992 American Cancer Society (ACS) guidelines for routine screening³⁷: for clinical breast examination, every year for women older than 40 years and every 3 years or less for women aged 20 to 40 years, and for mammogram, every 2 years or less for women aged 45 years and older. Women aged 40 to 44 years were excluded from mammogram analyses because of the quota sample structure. An age-related screening "rigor" variable was also included, reflecting the fact that the quota ages included groups of women for whom recommended screening intervals differed.

Independent Variables

Since language is an important component of modifiable aspects of the process^{38,39} of breast cancer screening, we chose to focus on linguistic aspects of acculturation. Other indicators of acculturation (recency of immigration, proportion of life spent in mainland US, age at immigration, whether respondent was first or second generation, and language of interview) were available; however, these were not included in our acculturation scale or multivariate models because they were highly correlated and displayed strong multicollinearity with the acculturation scale.⁴⁰

TABLE 2—Selected Characteristics (%) of the Sample of Hispanic Women (n = 907^a), by Acculturation Level: New York City, 1992

	Acculturation		P
	Lower (n = 307)	Higher (n = 600)	
Age, y			
18–44 (n = 362)	32.0	55.4	
45–54 (n = 201)	23.2	20.2	
55–64 (n = 188)	23.5	15.3	
≥65 (n = 156)	21.3	9.1	.001
Education, y			
<12 (n = 424)	58.8	23.1	
12–15 (n = 379)	33.2	58.6	
≥16 (n = 104)	8.0	18.3	.001
Household income, \$			
<20 000	46.7	30.0	
≥20 000	16.0	51.1	
Missing ^b	37.3	18.9	.001
Usual site of care			
Private doctor's office	39.4	45.4	
Hospital outpatient department	15.6	14.8	
Public health clinic	8.1	6.3	
HMO	10.8	8.6	
Emergency room	8.9	9.5	
No usual site	17.1	15.4	.525
Insurance status			
Private insurance (n = 337)	25.3	60.3	
Only Medicare or Medicaid (n = 321)	41.7	23.1	
Uninsured (n = 227)	30.2	15.0	.001
Proportion of life spent in mainland US, %			
<25 (n = 343)	37.5	9.9	
26–50 (n = 317)	43.2	20.2	
51–75 (n = 181)	16.4	27.8	
>75 (n = 53)	2.8	42.1	.001
Age at immigration, y			
≤16 (n = 218)	8.3	54.7	
>16 (n = 689)	91.7	45.3	.001

^aIn some categories, n's may not add up to 907 because some women refused to answer the question or answered "Don't know." There were no significant differences between the numbers of women with higher and lower acculturation scores in the "don't know/refused" category for any variable except income.

^bIncome was missing for women who refused to answer the question or answered "Don't know."

Our acculturation measure was a continuous variable based on a 12-item scale (available from the authors). These items were drawn from a 26-item acculturation scale developed by Burnam et al.²³ and later validated, in this shortened form, in a New York City Hispanic population by Epstein et al.²⁴ This scale was reliable in our sample (Cronbach $\alpha = .93$). The 12 items asked about language and media (television, radio, books, magazines, newspapers) use in a variety of situations (work, home, neighborhood, shopping) and with different people (including spouses or partners, children, parents, and friends). For each item, the 5 response options were as follows: 1 = only Spanish, 2 = mostly Spanish, 3 = Spanish and English, 4 = mostly English, and 5 = only English. Acculturation level was calculated as a mean score of these 12 items (1 = least accultur-

ated, 5 = most acculturated).²³ (For ease of understanding, in Tables 1–3 the acculturation score is dichotomized into "lower" [score ≤ 2.5] and "higher" [score > 2.5]. In Table 4 [multivariate models], the acculturation score is continuous.)

Controlling variables included socio-demographics (age, education, marital status, income, employment); health status (self-assessed 5-item measure, ranging from "poor" to "excellent"); site of care; presence of a usual source of care; insurance status (uninsured, public insurance only [i.e., Medicare or Medicaid], or private insurance); and cancer attitudes and beliefs.^{8,11,41–48} Since approximately 30% of the respondents refused to provide data on income, this variable was included in the multivariate analyses by keeping the refusals as a separate dummy variable.

Cancer attitudes were measured with the Cancer Attitudes Scale.^{26,49} This scale includes an anxiety subscale (6 items, Kuder-Richardson-20 = 0.57) and a hopelessness subscale (8 items, Kuder-Richardson-20 = 0.65). Perceived risk for developing cancer was measured with 2 items ($r = 0.70$) and concern about cancer was measured with 2 items ($r = 0.72$).²⁶

Analysis

Bivariate analyses were performed to assess relationships among categorical variables. Statistical significance in cross-tabulations was evaluated with the χ^2 statistic. We tested for interactions between acculturation (dichotomized) and several potential effect modifiers with respect to screening use: education, insurance status, income, and health status.⁴⁷ For women who chose to do the interview in Spanish, an additional test for interaction between acculturation and language of the health care provider was performed. No significant interactions were found between acculturation and income, insurance status, or health status in predicting screening use. There was a tendency for education to modify acculturation's effect on screening; however, estimates for these interaction terms were highly unstable in the multivariate logistic regressions and were not included in the final models.

Stepwise logistic regression models assessed the effect of acculturation and controlling variables on each of the cancer screening outcomes. Variables that had at least 1 significant dummy (α level for stepwise regression = .20) were included in the final model. All models exhibited goodness of fit by the Hosmer-Lemeshow test.⁵⁰

The parameter estimates from the final multivariate logistic regression models were then entered into the logit function to calculate the adjusted probabilities of screening for each of the 5 levels of acculturation.⁵¹ An additional model was created for the subgroup of women who completed the interview in Spanish (n = 726). This model was the same as the overall final logistic regression model for the entire group (n = 907), with the addition (one at a time) of variables on language and its importance in the health care setting (whether the physician spoke Spanish, importance of physician's speaking Spanish, importance of someone in the clinic's speaking Spanish). All analyses were performed with SAS.⁵²

Results

A total of 908 Hispanic women completed the survey. The overall response rate

TABLE 3—Percentage (Unadjusted) of Hispanic Women Receiving Breast Cancer Screening, by Selected Characteristics: New York City, 1992

	Clinical Breast Examination		Mammography	
	Ever (n = 888)	Recent ^a (n = 882)	Ever (n = 542)	Recent ^a (n = 524)
Total sample	86.3	68.1	71.6	62.0
Demographic characteristics				
Age, y				
18–44	85.3	77.8
45–54	85.1	59.2	66.7	58.5
55–64	90.9	68.5	74.7	66.5
≥65	84.5	58.1**	74.2	61.2
Ethnicity				
Colombian	87.9	66.3	73.4	62.7
Dominican	80.5	64.7	66.9	53.4
Ecuadorian	85.3	69.6	68.4	62.5
Puerto Rican	92.6**	72.9	76.6	69.9*
Marital status				
Married	86.1	70.0	68.2	61.3
Single, divorced, widowed	86.5	66.7	73.6	62.2*
Socioeconomic characteristics				
Education				
<12 y	83.2	59.2	69.3	59.3
12–15 y	88.0	74.4	73.7	66.3
College graduate	92.4*	81.7**	78.0	65.8
Household income, \$				
<20 000	83.9	63.9	68.6	60.2
≥20 000	92.0	81.8	78.4	77.6
Missing ^c	84.2**	61.3**	71.1	55.7**
Employment status				
Unpaid	87.8	65.4	69.3	59.2
Retired	84.1	61.2	75.5	61.9
Part-time	87.5	70.4	67.4	61.9
Full-time	88.6	74.8*	72.5	66.4
Insurance status				
Uninsured	77.5	53.4	53.4	45.4
Medicaid/Medicare only	88.2	68.0	77.5	63.7
Private	91.0**	78.3**	76.3	70.3**

(Continued)

was 62.3% (includes all calls made to identify homes of persons of the ethnic and age groups of interest). Among women who qualified on the basis of age and ethnicity, the rate of refusal to complete the survey was 2.1%.

Table 1 presents the characteristics of the specific Hispanic subgroups. Dominicans tended to be younger and to have lower incomes than members of the other groups. A higher percentage of Puerto Ricans than of the others came to the mainland United States by age 16 years. Puerto Ricans were also more likely than the others to use English for the interview and to have some form of health insurance.

Table 2 presents selected characteristics of women with lower and higher acculturation scores. These characteristics were highly correlated with acculturation (proportion of life spent in the United States, age at immigration) or were significant predictors of screening use in the final multivariate model.

els (age, education, insurance status, income, type of site of care/usual source of care).

Having higher acculturation, having a usual source of care, having higher income, having health insurance, immigrating to the United States before the age of 16 years, spending a greater proportion of one's life in the United States, and use of English for the interview were each statistically significantly associated in univariate analyses with greater receipt of ever and recent clinical breast examination and mammography (Table 3).

The final multivariate logistic regression models (Table 4) showed that when other covariates were controlled for, women who were more highly acculturated were significantly more likely than less acculturated women to have obtained a clinical breast examination, both ever and recently ($P \leq .01$), and to have ever ($P \leq .01$) and recently ($P \leq .05$) received a mammogram.

The mean adjusted probabilities of screening as a function of acculturation are shown in Figure 1. For all tests, there is a linear increase in the adjusted probability of screening as one goes from least to most acculturated.

Of the 908 women interviewed, 726 chose to be interviewed in Spanish. These women were asked whether the doctor at their usual site of care spoke Spanish and about the importance of either their doctor's or other clinical personnel's speaking Spanish. Although 89% of the women with lower acculturation scores felt it was important that their doctor speak Spanish, only 49% of those with higher acculturation scores felt this was important ($P = .001$). Similar proportions of more and less acculturated women felt it was important that someone in the clinic speak Spanish (89% vs 51%, respectively; $P < .001$). Surprisingly, in this subset of 726 women, having a primary care doctor who spoke Spanish was not significantly associated with higher odds of receipt of ever or recent clinical breast examinations or mammograms (data not shown).

Discussion

Previous studies on breast cancer screening and acculturation have focused on Mexican Americans in California and the Southwest; this study is unique in its focus on Colombian, Dominican, Puerto Rican, and Ecuadorian Hispanic women in New York City. For these women, greater acculturation was significantly associated with higher rates of screening by clinical breast examination and mammogram. This relationship held after adjustment for socioeconomic status, health status, demographic and health system characteristics, and cancer attitudes and beliefs. Consistent with the findings of previous studies, having insurance remained a major predictor of screening use.¹⁶

Previous studies on breast cancer screening and acculturation have had conflicting results. Some found no statistically significant effect of acculturation on screening utilization,^{17–19,22,53} while others did find an effect.^{20–21} The studies that found no significant effect all^{17–19,22} used a broad measure of acculturation that included not only language use but also social patterns, family values, or ethnic identification. One of the studies that found a significant association between acculturation and screening used a measure that included language, ethnic identification, and birthplace,²⁰ and the other used only language chosen for the interview.²¹

Placing our results in the context of these previous conflicting findings is compli-

TABLE 3—Continued

	Clinical Breast Examination		Mammography	
	Ever (n = 888)	Recent ^a (n = 882)	Ever (n = 542)	Recent ^a (n = 524)
Health/health system characteristics				
Health status				
Excellent—very good	87.8	70.5	69.4	62.9
Good	86.9	70.8	74.8	66.7
Fair—poor	83.3	62.0*	71.0	58.6
Usual source of care				
Yes	88.7	71.5	75.4	65.8
No	73.6**	50.7**	48.7**	39.5**
Usual site of care				
Private doctor's office	89.5	69.8	71.7	62.9
Emergency room	87.7	72.8	71.1	59.1
Hospital outpatient department	89.6	75.0	88.6	80.5
Public health clinic	87.9	69.7	77.8	62.8
HMO/large health center	88.8	75.0	80.0*	69.5*
Acculturation				
Language preferred for interview				
English	95.8	86.1	81.0	75.9
Spanish	84.0**	64.0**	70.4	60.4*
Age at immigration, y				
≤16	93.1	80.5	83.3	74.3
>16	84.3**	64.5**	69.8*	60.1*
Proportion of life spent in mainland US, %				
≤25	76.4	59.0	60.0	51.9
26–50	87.5	69.1	72.7	61.9
51–75	90.6	67.4	76.3	67.7
>75	98.1	84.6	87.1	80.6
Born in mainland US	95.0**	87.3**	81.2**	71.4*
Acculturation ^d				
Higher	94.5	80.8	79.4	73.4
Lower	82.2**	62.0**	68.9*	58.3**
Cancer attitudes and beliefs				
Cancer anxiety scale				
High	84.6	66.0	70.6	61.1
Low	88.4	70.8	73.1	63.6
Cancer hopelessness scale				
High	84.3	64.3	70.1	69.2
Low	91.8**	78.9**	76.9	57.7**
Concern about cancer				
High	87.5	72.9	71.9	64.8
Low	85.3	64.4**	71.4	60.0
Perceived risk of cancer				
High	86.3	70.3	71.4	62.2
Low	86.2	65.7	71.8	61.9

^a"Recent" was defined according to 1992 American Cancer Society guidelines, as follows: for clinical breast examination, every year for women older than 40 years and every 3 years or less for women aged 20 through 40 years; for mammography, every 2 years or less for women aged 45 years and older. (Hence, total n's do not add up to 908.)

^bNot applicable.

^cIncome was missing for women who refused to answer the question or answered "Don't know."

^dMean acculturation scores (see text) were as follows: for clinical breast examination, ever vs never = 2.2 vs 1.7*, recent vs not recent = 2.3 vs 1.8*; for mammography, ever vs never = 2.0 vs 1.7*, recent vs not recent = 2.1 vs 1.8*.

* $P \leq .05$ for the group (cell); ** $P \leq .01$ for the group (cell).

turation scales and because it is valid.^{58,59} We chose to focus on the linguistic aspects of acculturation because of their relevance to interventions targeting the delivery of health care.

Measures of acculturation that focus on language use have another advantage over broader measures of acculturation: one can establish that language use is associated with the screening behavior. With mixed acculturation measures, components unrelated to the behavior of interest could lower the association between language use and health behavior, perhaps explaining the inconsistency of previous findings in studies of acculturation and health practices of Hispanic adults.^{23,24,60}

The second area of controversy is the conceptual framework within which acculturation operates. Limited proficiency in English is associated with socioeconomic factors known to be related to decreased use of health care services.^{21,61} If these factors are not controlled for, acculturation may simply act as a proxy for socioeconomic status.⁵⁴ Our inclusion of socioeconomic indicators (income, education, work status) in the multivariate models reduces this risk.

Also complicating the conceptual framework is the issue of how language influences health care use. Some see language as a communication barrier between health care provider and patient,⁶² while others emphasize the effect on screening practices of language as an access factor.²⁰ Viewing language acquisition as merely an "access factor" may be an oversimplification. Language influences perceptions, cognitive structure, and self-expression,^{63–66} which may affect how Hispanic women interact with providers. Thus, it is likely that language operates on both levels and that some combination of its effects contributes to the likelihood that a woman will obtain recommended screening.

As an example of language's complex role, we found that among the subset of women who chose to be interviewed in Spanish and who were the least acculturated, having someone in the clinic who spoke Spanish was not predictive of screening use. One implication of this finding is that simply introducing translators or Spanish speakers into the clinic, without addressing patients' level of acculturation, may not be sufficient to change behavior. It might be necessary, for example, to involve trained lay health workers from cultural backgrounds similar to those of the target population.⁶⁷

Further community- and practice-based research is needed to evaluate the effectiveness of tailoring cancer screening messages to the acculturation level of the women being served. Further study would also help to clar-

cated by the controversy over deciding how best to measure acculturation and determining the conceptual framework within which acculturation operates. With respect to the first area, some criticize the use of language preference alone as an inadequate measure of acculturation; they contend that the extent to

which a person has adopted core values of the host culture should be included.⁵⁴ Others argue that language preference is the best measure of cultural integration.^{55–57} Many now view language as a reliable shorthand measure of acculturation, because it accounts for the greatest portion of variance of accul-

TABLE 4—Acculturation and Adjusted Odds^a of Breast Cancer Screening in a Sample of Hispanic Women: New York City, 1992

	Odds Ratio (95% Confidence Interval)			
	Clinical Breast Examination		Mammography	
	Ever	Recent ^b	Ever	Recent ^b
Acculturation ^c	1.82** (1.30, 2.60)	1.35** (1.07, 1.71)	1.59** (1.17, 2.17)	1.34* (1.01, 1.79)
Usual site of care				
Private doctor's office	1.25 (0.60, 2.49)	0.84 (0.48, 1.44)	1.11 (0.54, 2.21)	1.13 (0.57, 2.21)
Hospital outpatient department	1.53 (0.66, 3.54)	1.24 (0.65, 2.35)	4.00** (1.58, 10.7)	3.40** (1.48, 8.02)
Public health clinic	1.55 (0.59, 4.28)	0.97 (0.47, 2.04)	1.82 (0.66, 5.28)	1.33 (0.52, 3.47)
HMO	1.47 (0.59, 3.79)	1.30 (0.64, 2.66)	2.02 (0.82, 5.15)	1.69 (0.73, 3.99)
Emergency room	1	1	1	1
No usual site	0.56 (0.27, 1.13)	0.43** (0.23, 0.77)	0.56 (0.25, 1.21)	0.56 (0.26, 1.22)
Education, y				
<12	1	1	1	1
12–15	1.24 (0.76, 2.04)	1.39 (0.96, 2.02)	1.12 (0.69, 1.83)	1.11 (0.70, 1.79)
≥16	1.86 (0.82, 4.71)	1.90* (1.05, 3.59)	1.25 (0.55, 3.10)	0.89 (0.41, 1.98)
Age, y				
20–44	1	1	NA	NA
45–54	1.48 (0.85, 2.62)	0.68 (0.33, 1.32)	1	1
55–64	3.20** (1.66, 6.35)	1.25 (0.61, 2.49)	1.71* (1.06, 2.80)	1.45 (0.81, 2.59)
≥65	1.16 (0.60, 2.25)	0.66 (0.31, 1.34)	1.17 (0.66, 2.07)	1.03 (0.54, 1.95)
Insurance				
Private	1.62 (0.92, 2.86)	2.10** (1.36, 3.24)	1.75* (1.00, 3.07)	1.49 (0.87, 2.57)
Public only	2.55** (1.47, 4.49)	2.26** (1.47, 3.51)	2.47** (1.38, 4.47)	1.74* (1.01, 3.03)
Uninsured	1	1	1	1
Income, \$				
<20 000	0.78 (0.41, 1.45)	0.70 (0.43, 1.10)	0.77 (0.40, 1.47)	0.56 (0.30, 1.04)
≥20 000	1	1	1	1
Missing ^d	0.90 (0.44, 1.82)	0.79 (0.47, 1.32)	1.01 (0.51, 2.00)	0.49* (0.25, 0.94)

Note. Only statistically significant variables from the final model are shown. 1 = reference category; NA = not applicable.

^aAll odds ratios are adjusted for acculturation, type of site of care/usual source of care, education, age, ethnicity, insurance status, marital status, health status, cancer anxiety score, cancer hopelessness score, cancer concern score, and income.

^b"Recent" was defined according to 1992 American Cancer Society guidelines as follows: for clinical breast examination, every year for women older than 40 years and every 3 years or less for women aged 20 through 40 years; for mammography, every 2 years or less for women aged 45 and older (40–44-year-olds excluded because of quota sample structure).

^cAcculturation is continuously scaled from 1 (least acculturated) to 5 (most acculturated). Odds ratios for this variable indicate increase in odds of screening per unit increase in the acculturation scale.

* $P \leq .05$; ** $P \leq .01$.

ify whether having health care providers with a common language or cultural orientation could lead to improved screening rates for Hispanic women.

Several factors should be considered in interpreting our data, including potential selection bias, use of self-report, and a potential lack of generalizability to persons without telephones or living in rural areas. The women who participated in this study may differ systematically from the nonparticipants; for example, participants may be more likely to have had screening. We do not have data on the nonparticipants. However, the refusal rate among those known to be eligible for the study was low (2.1%).

Use of screening services in this study was determined by self-report. Since the women received care from a variety of settings in New York City, validation of self-reports through medical record review was not practical. Several studies have established that self-reporting usually overestimates the preva-

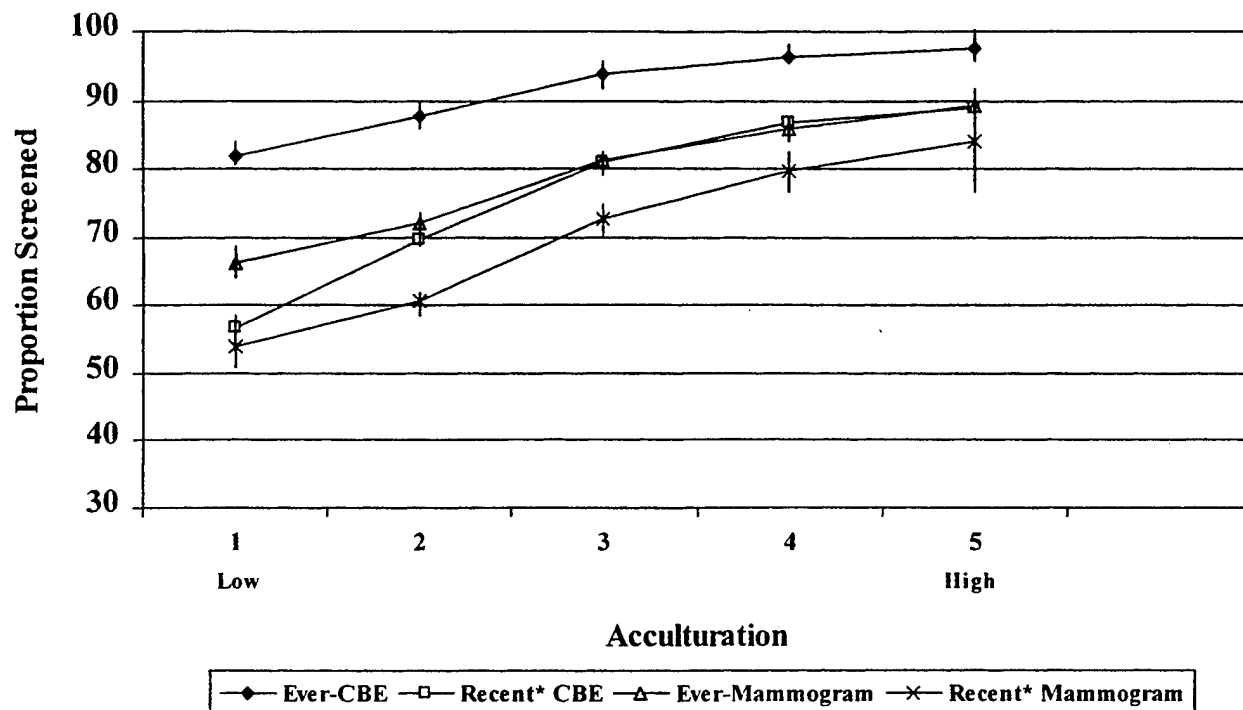
lence of screening.^{66–71} Characteristics that might influence the validity of self-reports, such as acculturation, education and socioeconomic status, have been controlled for in analyses assessing the sample as a whole.

The rates of receipt of clinical breast examination and mammography in our 1992 study seem high relative to commonly cited national rates, most of which are based on data from 1987 and earlier. However, our screening rates are consistent with those from more recent local studies³⁵ and with Behavioral Risk Factor Surveillance System data from the same period. For instance, a Centers for Disease Control and Prevention study of these data for 39 states⁷² found that age-adjusted proportions of women aged 40 years and older who received a mammogram in the preceding 2 years ranged from 43.8% to 65.2% in 1989 and from 63% to 79.7% in 1995.

While the vast majority of Hispanic residents of New York State resided in New York City at the time of the survey,²⁷ our data may

not be generalizable to Hispanic women living in, or migrating to, rural settings. In 1992, 79% of Hispanic households in New York City had telephones.⁷³ Personal interviews, the alternative to telephone interviews, are difficult to achieve in the economically depressed areas of New York City where many of the target populations live, because of residents' concern for security. Furthermore, in-person screening for quota samples is extremely inefficient. Despite this limitation, the quota sample is broadly representative of the ethnic groups living in the targeted areas.

An upward trend in screening use among Hispanic women, compared with older data, is reflected in our results and those of other recent studies.^{16,68,74} However, recent mammography use is still reported by a higher proportion of Anglo Americans (79%)¹⁶ than either Mexican Americans (61%)¹⁶ or our sample of Hispanic women (52%). Nationally, the same is true of recent clinical breast examination (66% [Anglos] vs 59% [Hispan-



Notes. Vertical line indicates the 95% confidence interval for that adjusted proportion.

"Recent" was defined according to 1992 American Cancer Society guidelines as follows: for clinical breast examination, every year for women older than 40 years and every 3 years or less for women aged 20 through 40 years; for mammogram, every 2 years or less for women aged 45 and older.

Adjusted proportions of women screened are calculated from the logit function based on the multivariate logistic regression models (see Table 3), which adjust for acculturation; type of site/usual site of care; education; age; ethnicity; insurance status; marital status; health status; cancer anxiety, hopelessness, and concern scales; and income.

FIGURE 1—Adjusted proportions (with 95% confidence intervals) of Hispanic women receiving breast cancer screening, level of acculturation.

ics]).⁷⁴ In our sample, recent clinical breast examination rates were slightly higher (68%), especially among the more acculturated.

The Department of Health and Human Services already recognizes the importance of language and culture in health promotion programs serving minority populations and has established a year 2000 goal to "increase to at least 50% the proportion of counties that have established culturally and linguistically appropriate community health promotion programs for racial and ethnic minority populations."⁹ Our finding of a strong association between a woman's level of acculturation and whether or not she receives recommended screening reinforces the importance of acculturation in the delivery of breast cancer screening programs to women in these Hispanic subgroups. Although the more acculturated women in this study had screening rates near or even exceeding those set as year 2000 goals—defined as 80% of Hispanic women aged 40 and over have ever received and 60% of Hispanic women aged 50 and over have recently received clinical

breast examination and mammography—less acculturated women still have a long way to go if they are to achieve those objectives. The fact that recency of immigration was associated with screening and was strongly collinear with acculturation suggests that targeting programs to areas with a high proportion of recent immigrants may be a useful way to reach less acculturated Hispanic women. □

Contributors

Ann O'Malley developed the research question, performed all data analyses, and wrote the manuscript for this paper. Jon Kerner and Jeanne Mandelblatt were both principal investigators on the National Cancer Institute study responsible for the collection of the dataset and contributed to writing the manuscript. Ayah Johnson provided statistical guidance for the project.

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